Bioethics Research Library at Georgetown University

https://repository.library.georgetown.edu/handle/10822/503786

Transcripts of the President’s Council on Bioethics (PCBE) Meetings 2001 - 2009

The Bioethics Research Library is collaborating with Georgetown’s University Library to digitize, preserve and extend the history of Bioethics.

Please tell us how this access affects you. Your experience matters.

Visit us at https://bioethics.georgetown.edu/.

Interested in learning more about President’s Council on Bioethics? You can visit their website as it appeared on the last day of its charter. There you can learn about the council members, browse their reports, and locate background materials. The website is hosted by the Bioethics Research Library and can be found at:

https://bioethicsarchive.georgetown.edu/pcbe/

Materials produced by the President’s Council on Bioethics are government documents and in the public domain. When citing this document please note the source as Bioethics Research Library and the appropriate Digital Georgetown hyperlink

Collection Permanent Link: hdl.handle.net/10822/559325
Meeting Transcript
March 3, 2005

The Sphinx Club
1315 K Street, NW
Washington, DC 20005

COUNCIL MEMBERS PRESENT

Leon R. Kass, M.D., Ph.D., Chairman
American Enterprise Institute

Benjamin S. Carson, Sr., M.D.
Johns Hopkins Medical Institutions

Rebecca S. Dresser, J.D.
Washington University School of Law

Daniel W. Foster, M.D.
University of Texas, Southwestern Medical School

Francis Fukuyama, Ph.D.
Johns Hopkins University

Robert P. George, D.Phil., J.D.
Princeton University

Alfonso Gómez-Lobo, Dr. phil.
Georgetown University

William B. Hurlbut, M.D.
Stanford University

Charles Krauthammer, M.D.
Syndicated Columnist

Peter A. Lawler, Ph.D.
Berry College

Paul McHugh, M.D.
Johns Hopkins University School of Medicine

Gilbert C. Meilaender, Ph.D.
Valparaiso University

Janet D. Rowley, M.D., D.Sc.
The University of Chicago

Michael J. Sandel, D.Phil.
Harvard University

Diana J. Schaub, Ph.D.
Loyola College

James Q. Wilson, Ph.D.
University of California, Los Angeles

INDEX
SESSION 1: AGING AND CARE-GIVING: LESSONS ON ASSISTED SUICIDE FROM THE OREGON AND THE NETHERLANDS' EXPERIENCES

CHAIRMAN KASS: Good morning. Welcome to Council members. Welcome to members of the public to this, the 20th meeting of the President's Council on Bioethics. We recognize the presence of our Executive Director, Yuval Levin, who is the Designated Federal Officer in whose presence this is a legally constituted meeting.

I am not quite sure what it means that the President's Council is meeting in the Sphinx Club. If anybody has reflections on that, we can take them later on.

Before we come to the morning’s business, we have a few cheerful announcements that I'd like to share with you. First of all, as you have already heard, our colleague, Robby George, is the winner of this year's Bradley prize.

Second, our law clerk for several years, Michelle Powers, has landed a wonderful job as counsel to the House Government Reform Subcommittee on Criminal Justice, Drug Policy, and Human Resources, where she will be working on the Subcommittee with jurisdictional oversight of the FDA and other drug, science, and bioethical issues. I want to thank Michelle for, really, her wonderful service to the Council, and wish her all the best in her new job. Michelle, please.

This morning we continue the Council’s work on the subject of aging and caregiving. All four sessions today in one way or another touch on that subject, and the first session is entitled "Lessons on Assisted Suicide From Oregon and Netherlands Experience."

For the better part of a year, the Council has been considering a wide variety of ethical and social issues connected with the arrival of a mass geriatric society, with some special attention to caring for and caring about people who can no longer care for themselves. Prime case: persons suffering from Alzheimer's Disease and other dementias.

We have deliberately chosen to take a broad and humanistic view, trying to shift the focus from the more dramatic, explicitly very end-of-life dilemmas that dominate public consciousness and even academic bioethics literature: when to pull the plug or the feeding tube; the ethics of assisted suicide and euthanasia.

With several millions of people now, and soon, to be immersed in a decades long period of debility and dependency, it has seemed to us more responsible and more urgent to focus on how these people should — shall and should live amongst us throughout that period than how to ease them out of life at the very end.

It has not been the Council’s intention explicitly to take up the subjects of euthanasia and assisted suicide in their own right, for reasons just given; and the purpose of this morning's session is not to revisit all of the, I think, adequately articulated moral issues and arguments on this subject. But I think we would be remiss not at least to pay attention to what has been going on in this area, particularly because, when one talks about care for the elderly and decisions to forgo life-sustaining treatment, this topic invariably comes up, and it has been called to the Council’s attention that after a period of quiet, several states will probably soon be considering enacting Oregon-type legislation, partly to provide this option to persons unwilling to continue long-term struggles with their illnesses and disability.

Therefore, it seems fitting for us to inform ourselves on the current state of affairs in those two Western jurisdictions where physician-assisted suicide is legal, the Netherlands and our own state of Oregon. We would like to know who is choosing it, why, when, how, and especially under what form of monitoring and assessment.

We are very fortunate to have with us this morning to present findings on this subject Dr. Herbert Hendin, who is the Medical Director of the American Foundation for Suicide Prevention and Professor of Psychiatry at New York Medical College.

Dr. Hendin's studies of suicide have won him wide recognition here and abroad, resulted in his
receiving the prestigious Louis I. Dublin Award of the American Association of Suicidology. For the past several decades, he has focused especially on assisted suicide and euthanasia and their impact on end-of-life care. He has followed closely the developments in the Netherlands and in Oregon, and it is a great pleasure to welcome Dr. Hendin to the Council this morning.

DR. HENDIN: Thank you, Leon. I thought — I was speaking to some of the Commissioners before we started today and explaining to them how I became involved in this issue, and I thought it might be helpful for you to know something about that and particularly just what the American Foundation for Suicide Prevention is. It might give you a better context for the rest of my remarks.

The Foundation was formed, and I was involved in its formation, 17 years ago by scientists and lay people who were concerned with the problem of suicide, and we were modeled after the American Cancer Society or American Heart Association that funded research into suicide.

We do a certain amount of intramural projects; that is, projects done by scientists directly connected with the Foundation, but we were not formed in any way over the issue of assisted suicide and euthanasia.

A few years later they became public issues, due to — actually, then it was Derek Humphrey and Jack Kevorkian who brought it to the public, and we had to — we were asked about it. In fact, our name in those days was the American Suicide Foundation. So people would call and say, are you for it or against it?

In any case, we had to look into it, and I was asked with Gerry Klerman, who was then Chair of our Scientific council, was the former head of what used to be called The Drug and Mental Health Administration, to look into it. Unfortunately, Gerry died before we — about a month before we published our first paper on it.

It was clear that you weren't going to be able to know too much about it without going to The Netherlands and studying The Netherlands firsthand, because that was the one place where it was in practice, and it was legally sanctioned for about 20 years. It was sanctioned then only in case law. Eventually, about six or seven years ago, it was incorporated, or actually less than that, into a statute. But it was basically permitted by a series of case laws prior to that.

So I ended up going to The Netherlands and actually made four trips there. The Dutch were interested in having me, partially because of the prestige of our organization — by that time, we had virtually every scientist connected with suicide in this country and a good number of those abroad involved with the Foundation — and partially because they knew that my interest came from the fact that I had studied suicide among people over 60, and the large percentage of them are motivated by depression associated with physical illness, and I and Gerry Klerman had a concern that a lot of people who were physically ill or seriously ill or terminally ill over the age of 60 were going to request assisted suicide and euthanasia and perhaps not be treated for problems, both medical and psychological, that they could be treated for.

I didn't go to The Netherlands thinking that end-of-life care was going to be worse than it is here because I had a very low opinion of end-of-life care in this country at that time, and I think the Dutch, sensing that, thought that the more I saw about what they actually did, the more I would be persuaded of the merits of their system. So they made accessible to me the doctors who were the leading practitioners of assisted suicide and euthanasia, and I got to interview them, hear their cases, and talk to the people who were doing the Dutch government sanctioned studies on the matter.

I think, from the standpoint of the Dutch, I probably was a poor pupil, because I didn't come away with the conclusion they wanted me to come away with. I was more alarmed, and I felt that end-of-life care was far behind that in this country, and I was persuaded, and I will present you the evidence for that, that a large measure of the difficulties had to do with the fact that there was an easier option available to them.

So with that as a background, let me begin. I have added the word suicide to the title, because I really don't think that you can fully understand assisted suicide and euthanasia without reference to suicide, particularly because suicide in connection with medical illness is a major problem with an elderly population, and they become intertwined in ways that I will try to indicate.

So I'd like to begin by saying that medical illness plays an important but neglected role in 70 percent of suicides over the age of 60. We have studies to that effect.
suffering associated with serious or terminal illness. Depression associated with physical illness has been assumed to be the natural and inevitable consequence of being terminally ill. These assumptions provided the impetus for giving legal sanction to assisted suicide and euthanasia.

Study of The Netherlands is helpful in understanding the relation of suicide to assisted suicide and euthanasia and the possibilities of making both seem less of a necessary option for sick older people.

The Dutch experience also served as a stimulus for the assisted suicide law in Oregon, the one U.S. state, up to now, that has sanctioned it. I would like to examine with you how assisted suicide and euthanasia operate in practice in The Netherlands, how assisted suicide operates in Oregon, and how both relate to suicide, particularly among the elderly.

Legal sanction for assisted suicide and euthanasia began in The Netherlands in the late 1970s. The Dutch try to regulate assisted suicide and euthanasia within established guidelines which are: That the patient must make a well-considered, voluntary request; the patient must be experiencing intolerable suffering that cannot be relieved; there must be consultation with a second physician; and all cases of assisted suicide and euthanasia must be reported.

Charges of abuse led the Dutch government to sanction 1990, 1995, and 2001 studies of assisted suicide and euthanasia, but gave physicians immunity for anything they revealed. Most violations of the guidelines are evident from these studies.

Over 50 percent of physicians have suggested, or feel free to suggest, euthanasia to patients, which compromises the voluntariness of the process. The majority of Dutch cases were not reported, which by itself makes regulation impossible.

Reporting is done after the fact. Only the doctor can tell us what happened, and several thousand patients who have not given their consent have their lives ended by physicians each year, and all of that is information that is not the result of my studies but is in the Dutch reports.

A quarter of physicians stated they had terminated the lives of patients without an explicit request — that’s quoting — from the patient. A third more of the physicians could conceive of doing so.

An illustration of a case presented to me as requiring euthanasia without consent involved the Dutch nun who was dying painfully of cancer. Her physician felt her religion prevented her from agreeing to euthanasia. So he felt both justified and compassionate in ending her life without telling her he was doing so.

I was actually — as shocked as I was by the situation, I was surprised that anybody would think that almost anybody from this culture, even if they had been an advocate, would have been impressed by that illustration.

It was given to me as indicating why physicians sometimes have to end a life without asking the patient, and it seemed to me that almost anybody from another culture would have said why wasn’t her right to end her life the way she wanted respected, if you feel that the issue is you should have the right to end your life the way you want to.

In any case, practicing assisted suicide and euthanasia appears to encourage physicians to think they know best who should live and who should die, an attitude that leads them to make decisions without consulting patients, a practice that has no legal sanction in The Netherlands or anywhere else.

Compassion is not always involved. In another documented case that is in the Dutch literature, a Dutch patient with disseminated breast cancer who had rejected the possibility of euthanasia had her life ended, because, in the physician’s words, it would have taken another week before she died, and "I just needed this bed."

Since the government-sanctioned Dutch studies are primarily numerical and categorical, they do not examine the interaction of physicians, patients, and families that determine the decision for euthanasia. We need to look elsewhere for a fuller picture. Actually, I put that on too fast (referring to the slide he was showing).

Other studies conducted in The Netherlands have indicated how voluntariness is compromised, alternatives not presented, and the criterion of unrelievable suffering bypassed. A few examples from these other studies help to illustrate how this occurs.

A wife who no longer wished to care for her sick elderly husband gave him a choice between
euthanasia and admission to a home for the chronically ill. The man, afraid of being left to the mercy of strangers in an unfamiliar place, chose to have his life ended. The doctor, although aware of the coercion, ended the man’s life.

A healthy 50-year-old woman who lost her son recently to cancer refused treatment for her depression and said she would only accept help in dying. Her psychiatrist assisted in her suicide within four months after her son’s death. He told me that he had seen her for a number of sessions when she told him that, if he did not help her, she would kill herself without him. At that point, he did.

He seemed, on the one hand, to be succumbing to emotional blackmail and, on the other, to be ignoring the fact that even without treatment, experience has shown that time alone was likely to have affected her wish to die.

Another Dutch physician who was filmed ending the life of a patient recently diagnosed with amyotrophic lateral sclerosis says of the patient, “I can give him the finest wheelchair there is, but in the end it’s only a stopgap. He is going to die, and he knows it.”

That death may be years away, but a physician with that attitude is not in a position to present reasonable and acceptable alternatives.

Euthanasia, intended originally for the exceptional case, became an accepted way of dealing with serious or terminal illness in The Netherlands. Palliative care became one of the casualties. Hospice care lagged behind that of other countries. Dutch deficiencies in palliative care have been attributed by Dutch palliative care experts to the easier alternative of euthanasia.

Now the Dutch, however, point out that they have reduced the suicide rate in the country by almost a third, from 14.3 in 1980 to 19.7 in 2002. You can see that reduction, the reduction in the total rate. But if you take a look, you can also notice that that reduction doesn’t really begin until the 50 age group. Forty to 49 it is insignificantly reduced. Fifty to 59, it’s 22.5 percent. Sixty to 69, 42 percent. Seventy and over, it is almost 36 percent.

PROF. SANDEL: What is the rate?

DR. HENDIN: You mean the actual rate of suicide for the country?

PROF. SANDEL: No. What do these numbers refer to?

DR. HENDIN: This rate — This is the rate, 14.7, 14.6 per 100,000.

PROF. SANDEL: Per what?

DR. HENDIN: Per 100,000. I’m sorry. That’s the way suicide numbers are usually presented, and I guess it really isn’t evident to anyone who isn’t spending their whole life with those numbers, that that’s the way — it is not as clear as it should be, but these are all per 100,000, and the percent reductions are here. But the most significant part of that reduction is in the population over 50. You can see that from there.

Here, I am presenting the total deaths by suicide in the three studies that they did, 1990, 1995, and 2001. But what we are looking at is, if you would add the number of deaths by assisted suicide and euthanasia to the total, then you could see that, actually, rather than having reduced suicide, the increase in suicide is really — it would really be enormous or certainly very significant.

The drop in the older age group appears to be due to the fact that older suicidal patients are now asking to receive assisted suicide or euthanasia. The likelihood that patients would end their own lives if euthanasia wasn’t available to them is one of the justifications given by Dutch doctors for providing such help. But as I tried to indicate, among an older population physical illness of all types is common, and many who have trouble coping with physical illness become depressed and suicidal.

Now in 1998 the Dutch government made an effort to stimulate palliative care at six major medical centers. The Dutch essentially have tried to address the problem without really formally ever acknowledging that there was a problem. Nevertheless, those of us who were concerned with what was happening there were pleased that they were, to some degree, addressing it.

So incentives were undertaken to train professionals caring for terminally ill patients. More than 100 new hospices were established, and there was no increase in assisted suicide and euthanasia cases from 1995 to 2001 compared to a 20 percent increase between 1991 to 1995.
There were these three studies. The first study showed that there seemed to be a trend of increasing numbers. The second showed a leveling off, and it is our hope that, if the educational program is successful, this will be reflected in the decrease in the number of cases of assisted suicide and euthanasia. However, most physicians have not had training in palliative care or end-of-life care.

Patient autonomy is an illusion when physicians are not trained to treat patients’ suffering. Choice for patients then becomes continued agony or a hastened death. Studies show that the less physicians know about end-of-life care, the more they favor assisted suicide or euthanasia. The more they know, the less they favor it.

Oregon is experiencing many of the same problems as The Netherlands but is not doing nearly as much to combat them. Although legalizing only assisted suicide and not euthanasia, Oregon’s law differs from the Dutch in another major respect.

When terminally ill patients request assisted suicide... no, actually, I left out something there. Yes, the intolerable suffering that cannot be relieved is not a basic requirement for assisted suicide in Oregon. That's by itself a very significant difference.

While Oregon is only practicing assisted suicide and not euthanasia, you don’t have to be suffering interminably. All that is required in Oregon — not that that is nothing, but it is an enormous difference psychologically in what happens — is a diagnosis of terminal illness with a prognosis of less than six months to live is considered sufficient. I suspect, if you ask — or I suspect that Joanne Lynn, who will be following me, will address the problems involved in deciding that somebody has six months left to live much better than I could.

It shifts the focus from relieving the suffering of dying patients to meeting statutory requirements for assisted suicide. It encourages physicians to go through the motions of offering palliative care, providing serious psychiatric consultation, or making an effort to protect those who are vulnerable. Well, actually, what I wanted to say was vulnerable to coercion.

When terminally ill patients request assisted suicide, the physician must indicate in Oregon that palliative care is an alternative. They are not required to know how to relieve either physical or emotional suffering. Without such alternatives, the physician — without such knowledge, rather — without such knowledge, the physician cannot present reasonable alternatives, nor are they required to refer a patient for a consultation with a physician knowledgeable about palliative care.

In only 13 percent of the first 142 requests for assisted suicide in Oregon was a palliative care consultation recommended, and we do not know how many of these recommendations were actually implemented.

Now let me say a word about the fact that a psychiatric evaluation is not required. Autonomy is further compromised by the failure to mandate psychiatric evaluation in cases of assisted suicide. Only if the physician believes the patient’s judgment is impaired must the physician refer the patient to a licensed psychiatrist or psychologist. A diagnosis of depression is per se not considered a sufficient reason for such a referral.

Like other suicidal individuals, patients who desire an early death during a serious or terminal illness are usually suffering from a treatable depressive condition. Studies have shown that non-psychiatric physicians are not reliably able to diagnose depression.

Patients requesting assisted suicide are usually telling us that they desperately need relief from their suffering, and that without such relief they would rather die. Treated by a physician who can hear their depression, understands their ambivalence — what I meant was that who can hear their desperation — treat their ambivalence, understand their depression, and relieve their suffering, their wish to die usually disappears.

The psychiatric consultation in Oregon is only concerned with the more limited issue of the patient’s capacity to make the decision for assisted suicide. As I indicated, the physician is usually, almost invariably, not in a position to decide whether or not that capacity is impaired. That is usually something that requires a psychiatric evaluation, and usually a psychiatric evaluation is the standard of care for anybody who is suicidal.

The story of Joan Lucas, whose suicide was facilitated and publicized by Compassion in Dying — and that’s an advocacy organization that is very active in promoting assisted suicide and euthanasia in Oregon and elsewhere — points out strikingly how such a gatekeeper role encourages seeking psychological or psychiatric consultation as needed to protect doctors rather than patients.
Joan Lucas, an Oregon patient with amyotrophic lateral sclerosis, attempted suicide. Paramedics were called to Joan’s house, but her children sent them away, explaining, "we couldn't let her go to the ambulance. They would have resuscitated her."

Joan survived her attempt and was assisted in suicide 18 days later by a physician who gave interviews about the case to an Oregon newspaper on condition of anonymity. He stated that, after talking with attorneys and agreeing to help aid Joan in death, he asked Joan to undergo a psychological examination. "It was an option for us to get a psychological or psychiatric evaluation," he said. "I elected to get a psychological evaluation, because I wished to cover my ass. I didn't want there to be any problems."

The doctor and the family found a cooperative psychologist who asked Joan to take an MMPI, a standard psychological test. Because it was difficult for Joan to travel to the psychologist's office, her children read the True/False questions to her at home.

The family found the questions funny, and Joan's daughter described the family as cracking up over them. Based on these test results, the psychologist concluded that whatever depression Joan had was directly related to her terminal illness and was a completely normal response.

His opinion is suspect, the more so because, while he was willing to give an opinion that would facilitate ending Joan's life, he did not feel it was necessary to see her first.

Without a proper psychiatric evaluation, it is not possible even to ascertain if a patient has impaired judgment that would make him or her not capable of an informed decision, as required by Oregon law. Without such a consultation, there is less likely to be an attempt made to understand and relieve the desperation, anxiety and depression that underlie most requests for assisted suicide.

It was hoped that Oregon would serve as a laboratory for the state, showing us how assisted suicide would work. This has not occurred, in part because the law was not written with such an aim in mind. Even more troublesome has been the restrictive "don't ask, don't tell" manner in which the Oregon Health Division, charged with monitoring the law, has interpreted their mandate.

The Oregon Health Division — I abbreviated as OHD — asked physicians participating in assisted suicide to provide only a minimum of medical information about their patients, and patients are not asked to complete or provide any information to the state.

Most of the patients are in hospice care, but OHD does not interview hospice staff, hospice nurses and social workers who may have the most knowledge of the patients. They are given no voice in the monitoring process, nor are physicians interviewed who, for whatever reason, did not comply with patients' requests for assisted suicide, and a high percentage of the cases are turned down by their own physicians who know them a long time and don't think it is appropriate, and then the patient is referred, very often by Compassion in Dying, to a physician — group of physicians who don't seem ever to find a case that isn't suitable, although the person's family physician in a very high percentage of cases doesn't seem to think it is appropriate.

To evaluate the end-of-life care provided these patients, the OHD investigators would have needed to interview these physicians, as well as those who participated in the assisted suicide. The data OHD collects doesn't make it possible to know what transpired in most cases. In fact, the cases we know are cases that the Compassion in Dying has chosen to publicize, and anybody carefully examining them finds that those cases are similar to the Joan Lucas case, cases that don't persuade you that the case was treated properly.

Now with regard to Oregon's claim that in yearly progress reports the OHD writes, and they usually publish them in the New England Journal of Medicine now, at least in summary report, and they are published, and they are printed on the Internet — They contend that assisted suicide — that patients who received assisted suicide were receiving adequate end-of-life care. But data from patient interviews, surveys of families of patients receiving end-of-life care in Oregon, surveys of physicians and the data from the cases where information has been made available indicate otherwise.

A recent study at the Oregon Health Sciences University — and that is the university that is composed of people who are basically — that university has been at the forefront of promoting assisted suicide and euthanasia — indicated that there is a greater percentage of cases of inadequately treated pain in terminally ill patients in Oregon since the Oregon law went into effect, and they examined before and after with regard to that.

The Foundation, evaluated end-of-life care in all 50 states. The Foundation and the Last Acts Program have no position on assisted suicide, but have a strong position on providing adequate end-of-life care.

Oregon received good marks for its use of advance directives, for not overusing intensive units, and in training Registered Nurses in palliative care. Oregon did poorly in nine other measures utilized in the evaluations, including a large number of nursing home residents in persistent pain; a small number of its hospitals providing hospice or palliative care; a small number of its patients able to die at home, which most patients prefer to do; and state policies that don’t encourage pain control and palliative care.

Improved psychological and medical care for people with incurable illness is crucial in its own right, but is also probably the best approach we can take to reducing suicide among the elderly.

The World Health Organization has recommended that governments not consider assisted suicide and euthanasia until they have demonstrated the availability and practice of palliative care for their citizens. All states and all countries have a long way to go to achieve that goal.

People are only beginning to learn that, with well-trained doctors and nurses and good end-of-life care, it is possible to avoid the pain of the past experiences of many of their loved ones and to achieve a good death.

In 1997, in rejecting a constitutional right to assisted suicide, the U.S. Supreme Court, in a sense, challenged the state to provide such care. The right to such care, embraced by a majority of the Court, is the right that patients should demand, and that every state and every country needs to meet. Thank you.

CHAIRMAN KASS: Thank you very much. Let me ask a couple of things, and then we can go around the room.

First of all, on this question of Oregon being a kind of laboratory for us to learn how this thing operates, you indicate that the requirements of the state are rather minimal to find out what is going on. To what extent does the existence of the Federal privacy legislation get in the way of anybody, even if they wanted to, getting the kind of accurate data that we want here?

DR. HENDIN: Well, to my knowledge, it certainly wouldn’t affect what the doctors report to the Oregon Health Division. One could make a case that whether the information should be made public is another matter.

On the other hand, the data could be made available in ways that don’t indicate who the patient is or who the doctor is, if one wanted to make that available. But you would think the Oregon Health Division would collect the information.

There is one line indicating the evidence that the patient is terminally ill. There is one line indicating the diagnosis. There is no evidence presented for any of those opinions, which you would have wanted to know was there. Were there X-rays? Were there this? How did you make the diagnosis?

So you don’t have the data, and they specifically don’t want any independent researchers to look at that data.

Now the fact is that the doctors are proceeding, who practice it, to publish the data on their cases. I mean, so they are doing it in journals, but not in a way where they are subject to a group like this or a medical group that would then question them about it.

So that it is sort of being done in a way that is not done in medicine. Normally, you would want feedback from people.

Now we have communicated — the study in Oregon — something I have been doing with Kathy Foley. We have been in touch with some of the doctors and asked them if they ever talked to the original doctor, which you assume you would do, if a doctor turned down your patient and is referred to you.

One of the doctors who published his case said, no, he didn’t. Then he said he admitted that probably he should. But that’s not the way in which they are going. They are going the way of the Dutch in the sense that they are not — the Dutch are now — three percent of the cases are referred for psychiatric consultation.

I mentioned a case where the doctor wanted a consultation of the psychologist to protect himself, but
— and initially Oregon doctors were doing those consultations, but they were very often pro forma, like this one: finding people who are on a list of people who believed strongly in it and weren’t looking too carefully at the case.

I think the Oregon figure, which initially there were 40 or 50 percent, has dropped to 13 percent who are referred for psychiatric consultation, and this is the kind of consultation they are getting. So they are moving in the same direction as the Dutch with regard to it. But it would be possible to make the data available while still protecting the confidentiality far more than they want.

CHAIRMAN KASS: And the second short question: What about the medical reimbursement for assistance in suicide? Are there financial incentives? How does that — does the state reimburse?

DR. HENDIN: Oregon is in a unique position that ways, because they have, almost unlike — not almost — any other state, they have stipulations about what you can be reimbursed for every condition. So they take very much priorities with regard to it.

The doctors in Oregon who work with this problem have the actual data. I remember their conclusions about it, though, which was that the amount that they are giving for palliative care at the end of life has been reduced dramatically. So that it is much easier to simply get your coverage for assisted suicide, and they think that that is a factor that plays into it, that Oregon has so severely curtailed the reimbursement for end-of-life care.

Of course, that is a factor that is going to be an issue all over. I interviewed the doctor who was probably the pioneer of assisted suicide and euthanasia in The Netherlands. So I am not quoting something he told me in private. He said that publicly, Pieter Admiraal.

He felt that by 2020 that the Dutch were going to have to be doing more cases of assisted suicide and euthanasia to cope with the problem of an increasingly elderly population. And he said to me, he was glad he wasn’t going to be around. He is a man my age. He was glad he wasn’t going to be around to see that happen. Nevertheless, he still favors assisted suicide and euthanasia in The Netherlands.

CHAIRMAN KASS: Thank you. Jim Wilson?

PROF. WILSON: Thank you very much, Dr. Hendin. It was a very revealing report.

I am reminded of the phrase of the famous English writer who objected to bear baiting, less for concern for the care of the bear than for concern for the human participants. I have the same feeling here.

Troubling as suicide and assisted suicide is for the patients, I am more troubled by what it does to the doctors who participate in it. And to state the matter very strongly, perhaps to overstate it, I worry that such laws will result in the corruption of the medical profession.

You have spoken to people in The Netherlands and in Oregon who have participated or who have not participated in assisted suicide. Is there anything, without quantitative data, drawing only on your own judgment, you can tell us about the characteristics of the physicians, their specialty, their consultation skills, their age, their personality, of those who participate frequently and those who are reluctant to participate?

DR. HENDIN: I can tell you a little, but it is not — You know, it is based upon interviews of maybe 25 or 30 physicians. I would caution you that this is not a scientific factual study like the material I tried to present.

I did get to interview, oh, six or seven of the leading practitioners of the practice, and they were the ones referred to me by the organization that was for it. What you tend to see is that those who are doing a number of the cases become somewhat hardened to it and are not terribly troubled by it.

I was struck by this, because when at one point when Leon and I were testifying before Congress on it, one of the doctors there claimed that the criteria for doing it — this was an advocate — was that you had to be deeply troubled by it, as though if you were deeply troubled by it, it was all right and, if you weren’t, it suggested something wrong.

I have pointed out to him in private discussions — I don’t know if I said it at that meeting — that my experience has been that, if you do five or six or seven or 10, somehow those physicians don’t seem so troubled.

The thing I did notice was that a number of family physicians who did one or two cases are
sufficiently repelled by it that they tell you they will never do it again, because they were troubled by it.

One thing that I should have mentioned — I don’t know how I omitted it. When I was indicating that the Dutch have made some progress, it’s too early to say whether it will be sustained — was that for the first time since they’ve had this training, a number of the doctors who had the training have written publicly that they regret cases that they put to death by euthanasia, and they wouldn’t have done them, had they had the cases now, had they known then what they now know about how to treat such cases.

Now you couldn’t have even seen a doctor publish that when I was doing my work five years earlier. So there’s been some change.

Now, actually, the person who has written most eloquently about what happens to physicians is the gentleman at your right. However, I think what I saw in The Netherlands supports what Leon was hypothesizing would happen, and that is just that.

So now I can say the medical profession supported this or it never would have happened, and part of the reason it isn’t happening here is that, so far, the American Medical Association has strongly opposed it, but, more importantly, about six or seven years ago they introduced a program of training doctors in end-of-life care.

I was telling a few people before we started, it has been dramatic the difference that has had upon doctors. So that 45 percent in their polls — I get confused on which Emanuel it is, but it’s one Emanuel — Rahm Emanuel is in the government. So it’s Ezekiel Emanuel who is the physician who studies oncology.

In his studies, 45 percent of doctors before the AMA had this program, were in favor of assisted suicide. It is now down to 18 percent, and euthanasia, which was up in the thirties, is now down to eight or nine.

Now the doctors are ahead of the public with regard to this, and the doctors who have been educated — and they are training them as they go forward — are in the vanguard of this. But there’s still a big disconnect between where the doctors are. The doctors are — It’s almost like smoking, where the doctors were the group that stopped smoking totally, and it’s taken longer for the public to recognize the effect.

So I think that’s so. I did not deal with that in this work, and I don’t feel that I have the kind of data to present. I was trying to present to you initially what we had data, but if you are asking for my impression of it, that’s my impression of it.

CHAIRMAN KASS: Rebecca Dresser, and then Gil.

PROF. DRESSER: Thanks, Dr. Hendin. I ask this question not as somebody who is pro-legalization. I have many reservations, but for the reasons you discussed, the quality of the decision making, the quality of the care, the messages sent. But I do think we have to think about this in a broader context.

We have a lot of different end-of-life conduct. We have the active measures you have discussed that are openly recognized and legal. Then we have, you know, certainly in our country, the under the table active measures and assisted suicide. Then we have so-called passive euthanasia, forgoing life-sustaining treatment, terminal sedation, stopping nutrition and hydration, risky palliative care, and all those things can contribute to a hastened death.

So it seems to me it has been very good to shine a really bright spotlight on the areas where physician assisted suicide and euthanasia have been legally permitted, but I think, to be fair or to really have the baseline, we would want to look at the quality of the decisions people are making about these other practices that are permitted or aren’t legally permitted but are going on under the table.

So I wonder if you think somehow there is a greater danger of misapplication in the Oregon and Netherlands situations you have described in terms of end-of-life practice versus the other practices we allow.

Then, secondly, I guess just having read and studied about this for a while, my impression is that the training part that you mentioned that has made a difference in The Netherlands is really crucial, because inevitably all of these decisions will be somewhat private and under the control of
physicians.

So certainly, whether something is legal or not will make a difference for some physicians, but in many, many cases the quality of the death decision will depend on how careful the doctor is, how informed the doctor is, and so forth.

DR. HENDIN: Well, I think the tendency to put all of those in one bag is a little bit part of the problem, because I think there is an enormous difference between these other measures.

So that the advocates of assisted suicide and euthanasia like to refer to it as assistance in dying, but everything is assistance in dying. Sitting at somebody’s beside is assistance in dying, and that is because there is something that people sense is different about the doctor actively intervening.

So I am not strongly in favor of — in fact, I am bothered by the notion of people calling this assistance in dying laws or something like that.

Now with regard to the under the table, it is kind of interesting. The big survey that was done of that was done by Timothy Quill, who was an advocate of it, and Dianne Meyer at Mount Sinai, who was also then an advocate.

Dianne Meyer concluded from the surveys that they did that it was two or three percent of physicians that were practicing it, who had at least at times assisted in suicide or practiced euthanasia, with or without consent, and actually the highest number of those were doctors who had done it without the consent of the patients. Eighty percent of them had done it without consulting patients.

She changed her mind about legalization, feeling that if that percentage of doctors would do it while it was still something illegal, given that kind of sanction, the tendency for the practice to become — for people to do things that would violate even the stipulations of the law, which is what we have seen in The Netherlands, that most of the cases that are not reported are cases that don’t meet even the Dutch requirements, which are fairly liberal, which basically say, if you meet those requirements and report it, that’s it. They don’t report it.

So that I think that legalization, contrary to what is often said, that somehow you are going to regulate it, is going to give sanctions to things that are worse. That’s what I think happened in The Netherlands.

There may have been a second part to your question that I’ve forgotten.

PROF. DRESSER: Well, I guess one thing I want to point to, though, is: When patients make decisions to forgo care even, the sort of most acceptable end-of-life decision, we want to be sure they are competent. We want to be sure they are taking advantage of treatment for depression, if that is something that could help.

DR. HENDIN: Now I remember.

PROF. DRESSER: And so forth. But we don’t really make sure that all those things happen.

DR. HENDIN: Let me address that, because I think there is no question that that is something we would want to make sure of.

On the other hand, in actual practice the decisions that are being made to withdraw life support, let’s say, or to forgo care are usually being made in hospitals, and this is something that Joanne Lynn can address better than I can, but I have been involved in this enough to know that in hospitals it goes through an enormous amount of review before that is done. There are ethics committees. There’s consultation. There’s a great deal of things that happen.

Most of the assisted suicide cases die at home. So there isn’t — or euthanasia cases. There isn’t that kind of regulation. Now is that regulation perfect in every hospital in every case? I don’t know, but I’m sure it isn’t. But I think there is still a difference.

CHAIRMAN KASS: Gil Meilander, then Peter.

PROF. MEILAENDER: Dr. Hendin, there is an aspect of this issue that puzzles me, not because I am in favor of assisted suicide or euthanasia — I’m not — but just because it puzzles me.

I can think of a few ways of responding, but I’d be interested to hear how you would respond. This is the issue. There’s a sort of a Catch 22 for me here. On the one hand, many of these patients who
might seek euthanasia or assisted suicide are suffering from depression, could be treated and helped, and they might not request it, if that were the case.

On the other hand, if I am dying, seems to me that's a good reason to be depressed. You know, I'm not under some obligation to die feeling chipper about it. So I'd like you to think about that a little bit. I mean, I understand that, on the one hand, if we dealt with the depression, we might limit the number of requests for euthanasia or assisted suicide. On the other hand, it just seems there is something appropriate about being depressed when you are dying.

Now maybe that's a layman's understanding of depression, and you are going to correct it. But I'd like to hear you talk about it a little bit.

**DR. HENDIN:** The fact of the matter is that the overwhelming majority of people who are terminally ill are not clinically depressed. There is a difference. That doesn't mean that they are cheerful about dying or looking forward to it, but they are not clinically depressed.

They have the same ratio. It's about 60 percent in the highest studies that are, and they are certainly not asking for suicide, and those who are depressed aren't treated. Now that doesn't mean that they become, as you say, not sad about dying, but the interesting thing is that those who are treated — and I could give you just innumerable examples of patients.

You don't get requests in your practice in this country, because patients will tend to assume that you — as a psychiatrist and the law, they are not going to assume that you are going to assist them with it. But the first patient that I ever had that requested assisted suicide was referred to me by a colleague, and he was similar to a case that Timothy Quill published.

He had an acute leukemia, and with medication he had a 20 percent — 25 percent chance of surviving, and he was devastated by the news. He was a young professional in his thirties, and a colleague referred him to me.

He couldn't even discuss it with his wife, because he was kind of resentful that she was going to be going on with her life and her career and he wouldn't. So he couldn't. And I saw him for a few visits where he was able to talk about it. He decided that he would take the treatment, which was only a quarter, 25 percent. But he also — I was able to arrange for him to have one meeting with him and his wife and meet, and he opened up the discussion between them.

Now this man did not respond to the treatment, and he lived only four or five months, but he told me that in some ways he was closer to his wife in that period in a way he hadn't been — they were both very busy pursuing professional careers — since the time they first met, and he also became closer to his parents in that period, and I was in touch with him until the day he died, and he was very grateful to have had these four to five months, even though the treatment didn't work and even though he died.

I think that people like Joanne Lynn or Kathleen Foley could tell you these examples many, many times over. Now he had gotten very good medical treatment, that I was not providing, but we made sure he did. So that he had relief from his symptoms. It's not just the psychological symptoms. It's that they know how to relieve more than just pain today, and most people can be made comfortable; and if you stay with them until the end, they are usually grateful for that fact. So that's my sense of it.

**CHAIRMAN KASS:** Gil, did you want to come back? Peter Lawler, then Robby.

**PROF. SANDEL:** Could I just ask Gil a question about that point?

**CHAIRMAN KASS:** Please.

**PROF. SANDEL:** I was intrigued by your question. Is the intuition underlying it that people who are terminally ill or approaching death, that for them it is somehow fitting or appropriate that they want to die, that it eases them into it, that there is something fitting or appropriate to that?

**PROF. MEILAENDER:** No. My intuition is that there is no easing into death and that, therefore, one should — It wouldn't surprise me if anyone was depressed by the coming. So if I am understanding you — I'm not sure — I mean, part of the thing that — In fact, what I thought you were going to say — one could say, well, it's also appropriate that they should have pain or something like that. I obviously don't think that. I would want to relieve that, and the example Dr. Hendin gave of sort of relieving a certain kind of emotional suffering is significant. But you should be sad when you are going to die, it seems to me.
PROF. SANDEL: So the reason maybe we should think twice about treating it is that it is appropriate, and we shouldn't want to lift it.

PROF. MEILAENDER: Yes, just in the same way I feel that, if I've been married for 50 years and my wife dies, you shouldn't come around four months later when I am still dragging a bit and say, well, you know, life goes on, cheer up. It seems to me, there are experiences in life that are profoundly saddening, and it's the right reaction to have, and I wouldn't exactly want — I mean, I don't — It was a nice example.

I was going to say I wouldn't exactly want to relieve it. That is not quite right either, but I am just puzzled by the desire to relieve a reaction that seems to me to be appropriate to the human experience.

PROF. GEORGE: Wouldn't we then have to sort out the question of whether depression is a matter of sadness or whether there is a distinction between sadness and depression? I gather from Dr. Hendin's immediate response that — he shifted to the discussion of clinical depression — that he might have something here in mind different distinct from sadness.

PROF. MEILAENDER: No, and that's why one of the first things I said when I asked him the question was, you know, it might just be a layman's understanding of depression and, were it not sufficiently sophisticated, I understand that that might be part of my problem.

DR. HENDIN: I think the case that I mentioned earlier where I spent many hours with the psychiatrist who assisted in the suicide of a woman who was in perfectly good health in her fifties but whose son had died a few months earlier of cancer is an example of that.

I certainly wouldn't question — I don't think you ever totally get over the death of a child who dies when he is thirty. So you are going to live with it. On the other hand — On the other hand, you do get over the impulse to kill yourself, and just with time. And while I don't see anything inappropriate in her being depressed or sad or even if she was both, but if she were suicidal, you would want to do something about it; and if you did nothing else but say, if you feel the same way in two years, let's talk about it, you would have gotten a difference.

What was inappropriate was acting while she was in that mood. You know, while you say somebody shouldn't tell you to get over the sadness, they also shouldn't tell you you are never going to get over it, so you might as well end your life, which essentially was what he did. He supported.

PROF. MEILAENDER: I understand that, and there's a whole half of me that agrees with it. The alternative — and this will probably sound either offensive or just simplistic to some. The alternative is to say, no, I understand why you feel that way; I'd feel that way if I were in your shoes; you should feel that way under these circumstances, but you ought not commit suicide, no matter how you feel. I mean, that is an alternative.

DR. HENDIN: I don't think — I'm never in favor of telling people you ought not. I think what you —

PROF. MEILAENDER: Oh, I'm in favor of it a lot of times.

DR. HENDIN: But not in terms of suicide. In terms of suicide — I agree with you about other things, by the way, but not in terms of suicide. You don't reach people by telling them that you ought not. It's the way people try to put somebody in a hospital, saying go in the hospital because you are suicidal. Well, the person wants the freedom to end their life. They are not looking to go in the hospital where they won't have that freedom.

You can reach them if you reach them by understanding that anybody who feels that way is pretty desperate, pretty unhappy, doesn't feel that life is worthwhile unless they can get relief, and you have to address them in terms of the possibility of that suffering being relieved rather than the fact that it's wrong, that it's going to hurt their children. Part of being depressed is that you don't care about those things.

So in that sense, you can't deal with suicide simply as the fact that it's morally wrong alone. That is not an approach that is usually successful. I agree with you totally on the other thing, because you couldn't be a parent and not have the feeling you ought not.

When you were saying it, it reminded me of when my children were young and were watching television, and I told them that my wife and I agreed that there would be no television during the school week. So they went ahead and took it to their class, and the class and the teacher voted
unanimously that their parents were wrong. Fortunately, it wasn’t total participatory democracy. So nothing changed, and they both did better in school. So it isn’t that I disagree with you.

CHAIRMAN KASS: Before we go next in the queue, I think, since Gil’s perplexity on this is probably fairly widely shared, not only in this room but in other places, let me just push further.

How solid is the distinction between clinical depression and just very, very sad appropriate to a situation? This is an important matter here, because if you make something into a medical condition, then you think about it a certain way. If it is simply a profoundly disquieting response to life experience, you treat it another way, and maybe that is a distinction which, if Mike Gazzaniga were here, he would say, that is a distinction without a difference; it’s really — you know, the brain is in a certain way, regardless.

DR. HENDIN: The difference between sadness and clinical depression is very —

CHAIRMAN KASS: Let’s say grief, serious grief and clinical depression.

DR. HENDIN: Yes. The difference — there are numerous differences, but the duration of time is one of the differences. In addition, there are symptoms of depression that you must meet, and they are not what you just see in cases of sadness. Sometimes where you think somebody would be depressed but they are not, and they may want to die for other reasons than being depressed. So that’s another issue we could deal with. But there is the depression itself.

I mean, you don’t see the kind of total and global insomnia. You don’t see the resort to substance abuse, because of the need for relief. You don’t see the changes in appetite, in energy. A lot of different things have to be met, and a fair number of those criteria have to be met.

Now with regard to some of the other things, having worked with suicide a long time apart from just suicide where people are wanting to do it at the end of life, and the few cases that I have seen I always suspected something that is going to be confirmed by a group in Oregon.

It is an unpublished paper that I got to see. I don’t think I would have got to see it if I hadn’t been invited here, and people knew I was coming here. So they wanted me to see different positions and different points of view, but it is a paper that indicated — Somebody did a study of cases that requested assisted suicide and were helped in assisted suicide in Oregon outside the legal system, and they interviewed the families of a large number of these people.

The thing that came out in it is that the people at the end of life that asked for this were not suffering terribly, but they were people who had known for 30 years, 20 years, 15 years, 10 years, that when the end of life came — that when they were near the end of life, they would want assisted suicide. They would want to control their deaths, and they were people who had throughout life an inordinate need for control of circumstances, didn’t like the feeling that they would be needing help in some situations.

That’s a separate problem than just depression, although depressed people often make conditions for life: I won’t live unless this happens, that happens, this happens in my job. That kind of need for control is something that I have seen in suicidal patients throughout the years that often distinguishes them from depressed people.

The truth is that, if you are sick at all, you have to surrender a certain amount of control when you do need somebody’s help. But if that’s the case, we would be legalizing assisted suicide for a problem of a certain small percentage of the population that needs to control every circumstance in life. Thank you.

CHAIRMAN KASS: Peter Lawler, then Robby, and then Alfonso.

DR. LAWLER: So I thought your presentation was basically very optimistic, almost in spite of itself. It seems to be your opinion that almost nobody who is terminally ill who has physical pain and depression reasonably under control would want to commit suicide, except for that small percentage of the population you were just talking about who have this desire to die a free death or something. And today, we can do better than ever in controlling physical pain and psychological distress, and things in these two areas will get better all the time.

So the more patients and physicians know about what we can do in terms of how palliative care, the less enthusiastic they become in terms of assisted suicide and euthanasia. So that sort of enthusiasm in our time turns out to be based either in ignorance or a willful misrepresentation of the facts.
So in this area, the doctors who have been educated are ahead of the public. It’s always good news to talk in terms of being ahead of the public. It means in the long term on this issue we who are against the Dutch law or the Oregon law will win.

So all we have to do is fend off these terrible laws in the short term, because in the long term the truth is on our side. Is that a correct statement of the facts?

DR. HENDIN: It’s a view I share, whether it’s correct. We are either both right or both wrong, but, yes, I think that if you don’t have legalization for 10 or 15 years, there’s a good chance the issue will become irrelevant, and that’s a position that I come from, is that I think — In addition, while I think it is necessary to have good end-of-life care, I have a more parochial view, that I work with the problem of suicide, and I think no suicide prevention measure for the elderly would be more effective than good end-of-life care.

So I have a special interest in that, just from what I have spent a lot of time in my life working with.

CHAIRMAN KASS: Robby, Alfonso, Ben and Janet is what I have.

PROF. GEORGE: Thank you, Doctor. I want to make sure I am correct about a premise that needs to be in place for a couple of questions that I have to make sense.

Am I right that the most common motive for suicide is depression? Are there other motives that are equally common?

DR. HENDIN: Most people who work with it wouldn’t say it’s the most common motive, but it is — for a lot of reasons that I hesitate to go into, it is certainly the condition that most accompanies depression. It is the highest risk factor for depression. So it’s a major risk factor. Other things enter into it.

PROF. GEORGE: You mean risk factor for suicide?

DR. HENDIN: For suicide, yes. It isn’t — it can be that the suffering of depression per se is the thing that somebody sees that I need relief from. Usually, other things have to accompany it, because the vast majority of depressed people don’t kill themselves.

PROF. GEORGE: If you remove depression from the equation, would most cases of suicide not have happened?

DR. HENDIN: I don’t know about most, but certainly a large number.

PROF. GEORGE: A large number?

DR. HENDIN: For instance, let me just give you one example of another factor.

We are honoring this year a Swedish psychiatrist who did a study of what happened in Russia under perestroika where alcohol became almost unavailable, It was taxed in such a way that people didn’t have it.

The drop in the suicide rate was dramatic. Now nobody is suggesting we are going to back to prohibition, but alcoholism complicates — or not alcoholism — Substance abuse complicates at least 50 percent of all of these cases.

So to say simply that one factor — and the motivation for suicide can be relief from other things than depression. People who are hopeless don’t feel that there is going to be any change. People who are desperate, who feel the need for immediate relief from their condition, are much more at risk. People who have high anxiety levels with the depression are much more at risk.

So as I say, nobody would question that, if you could relieve depression per se, you would do something. On the other hand, if you don’t relieve the accompanying conditions, it won’t be enough.

PROF. GEORGE: Okay. Good. In the Oregon case, do we have anything that we can hang our hat on as far as reliable data is concerned about the percentage of people who are legally assisted in suicide who have been referred for psychological or psychiatric examination to screen out depression and related factors? Is that 90 percent as a ballpark figure? Would it be two percent?

DR. HENDIN: I quoted the figure, and of the ones who — of the first some 100-some-odd cases that were referred for palliative care consultation. I would have to look it up on my own slide, but it was a very small percentage, and even of that percentage it was 15 or 20 percent — I think it was
even less — nobody knows whether they actually went. It means the doctor merely suggested that they should have a palliative care consultation.

PROF. GEORGE: Okay.

DR. HENDIN: And that was about — as I say, it was somewhere below 20 percent, and it’s in one of these slides.

CHAIRMAN KASS: Thirteen percent.

DR. HENDIN: Thirteen percent.

PROF. GEORGE: Okay.

DR. HENDIN: And the condition with regard to psychological consultation, as I said, The Netherlands have moved down to three percent, and I think the figure for psychological consultation in the last figures — that, they do publish in the Oregon report — is also below 20 percent.

PROF. GEORGE: Okay.

DR. HENDIN: It has moved down steadily, from 50 down to somewhere below 20.

PROF. GEORGE: Now can you tell us whether there is a significant difference in the success rate when it comes to treating depression as between terminally ill persons who are suffering from depression and for whom that is part of a suicide risk — between terminally ill patients and non-terminally ill patients?

DR. HENDIN: The data that we have so far indicates comparable success rates in treating —

PROF. GEORGE: Comparable success rates. They are not a significant distinction?

DR. HENDIN: Yes, but I wouldn’t say that we have enormous amount of data from it. So I wouldn’t say that it is a proven fact, but those who have published on it, those who are working with terminally ill patients claim that they are having approximately the same success.

PROF. GEORGE: And finally, to shift from depression to the question of pain, do we know of documented cases and, if so, do we know how many documented cases do we have of suicides, legally assisted suicides, in Oregon that have been motivated by untreatable pain, or effectively untreatable pain?

DR. HENDIN: We have different studies with different results with regard to it. The studies I cited, which were often families interviewed afterward, they showed a high degree of unrelieved pain, and a higher degree since the Oregon law went into effect. I mentioned that.

A lot of the studies that are kind of odd by the advocates indicate that most of the people that they see are not suffering or in pain, which raises the question of why they are assisting them in the suicide, if they don’t have any dramatic symptoms, why they are doing this. But there’s the sense that they feel that, if the person requested it, that’s really sufficient if they can justify that they meet certain qualifications.

So the data is different. Last Acts found that nursing home patients in Oregon were getting very little pain relief. And as I say, if you read some of the papers from the advocates in Oregon, they claim that most of the cases they are seeing are not in enormous pain, and the same person who is about to publish this article that indicates that they were often people who wanted to control the end of their life, who is an advocate of it, claims that most of them were not in pain.

PROF. GEORGE: Thank you.

CHAIRMAN KASS: Alfonso, then Ben, then Janet.

DR. GÓMEZ-LOBO: I have a clarification question. I want to understand as best I can what is going on in Oregon, The Netherlands and in the deeper problem.

My question has to do with the following. The public justification of euthanasia and physician assisted suicide is usually autonomy. It is the idea that human individuals, autonomous individuals, have a right to determine or to control, as you say, the way that they die.

Now the information you have presented to us seems to suggest that that is precisely what is not going on. In other words, there are these problems of — well, not only involuntary euthanasia or
nonvoluntary ones, but there is the problem of depression.

First, I would like to know whether I am right on that. But second, I want to know, do psychiatrists try to "measure" the degree of autonomy and freedom of someone who is depressed? In other words, is there a point in depression where you can say, clearly say, this person is not making an autonomous decision, this person is really so encumbered by his or her problems that the decision is not the kind that you would hope people in a libertarian picture of human nature would make? Thank you.

**DR. HENDIN:** With regard to the issue of autonomy generally, I don't think the issue is even primarily an issue of depression, although it is a big part of it. I am addressing it, because it's the part of it that I am best qualified to deal with. But if all you have available to you is that you are going to have unrelieved suffering and to hasten death, and you are not dealing with a physician who knows how to relieve that suffering, I would contend that you don't have autonomy. That's not much of a choice.

It's such a choice that most people are going to say, well, if all I am going to do is continue in the way I am and nothing can be done for me, and the other alternative is I can get immediate relief, it may look like they have a choice, but they don't because they are not being given other alternatives.

That is, to me, the bigger problem, and that is a problem in the palliative care referral as much as it is an issue of the referral to a psychiatrist.

With regard to the second part of your question, by the time somebody has a diagnosis of depression, not the sadness that we were speaking about earlier, one of the key features of depression is the inability to see choices and alternatives. Everything tends to be seen in black and white terms.

So I don't think that most psychiatrists would feel that anybody who met the diagnosis of depression is going to be — now that doesn't mean that — that doesn't have total implications with regard to what you do, but wouldn't feel that anybody who is clinically depressed and meets the criteria is capable of an autonomous decision, because that is the nature of the condition, is that you don't see any possibilities for anything. You don't see choices or possibilities.

**CHAIRMAN KASS:** Ben Carson?

**DR. CARSON:** Dr. Hendin, thank you for that talk. That was very nice.

I would like to know what you think about who should determine the level of palliative care. The reason I ask that question is, of course, you could be talking about just pain relief or you could be talking about providing excellent pulmonary, toilet, taking care of decubitus ulcers and, therefore, preventing sepsis, and really good palliative care is going to be an extension of life, and to what degree are patients told that there is different levels of palliative care, and some of them will result in prolongation of your life, if they are not interested in prolongation of their life but they don't want to commit suicide?

**DR. HENDIN:** My feeling would be that anybody who is requesting assisted suicide should see an expert in palliative care, unless the physician there treating is one of the minority of physicians who is already expert with regard to it.

I think — I don't think that anyone can make and give you something that is simply designed to force you to extend your life, if there is a treatment that is going to do that. I mean, you are not allowed to continue somebody — I mean, somebody asked me in the meeting, talking before this meeting about this movie that has created such controversy about it.

Well, technically, I mean the movie is confused, because you are not allowed — A person can refuse to be on a respirator, and the hospital is required to remove you from a respirator. In practice, the situation is a little more nuanced than that.

Most hospitals have learned that people who, let's say, are quadriplegic — their immediate reaction is they want to die, and technically if they are on a respirator, by law you have no choice but to do that. In practice, they don't do it, because they have learned that, if you can wait a month or wean the person from the respirator, which may not have been possible in the case that was in that film but is possible, let's say, in Christopher Reeve's case where we know there was some impulse in the reverse direction. But once you are weaned, you are apt to feel differently.

So they tend to ignore the law, and nobody ever complains afterward. So the situation becomes
somewhat nuanced. But let's say you have somebody like this lady who was probably — possibly never going to be weaned from the respirator. Had she wanted to end her life a month later, the doctors would have — I mean, in that case of that film there was no psychiatric consultation, and this was supposedly a modern hospital.

It was just — and she developed an ulcer almost immediately, when any modern hospital, they move you around, and the likelihood of developing a quick ulcer are almost nil. But she would have been entitled to be removed after a month, and the hospital would have agreed to that, and this hospital would have had to agree right away that they weren't doing anything to make her feel better. So they would have had to.

So the situation becomes somewhat nuanced with regard to it. I mean, even — people usually are willing to live longer, if their living longer is going to be comfortable for them and productive, and you don't know that until you relieve the symptoms.

Strictly speaking, even in hospice care you do things that will relieve symptoms, and may prolong life. It's a judgment call in each case. But I would like to see that judgment made by somebody who is knowledgeable about all the alternatives, which most physicians currently are not.

CHAIRMAN KASS: Janet Rowley.

DR. ROWLEY: I have two questions and very different questions. One is pretty straightforward, I think, in terms of do you think there are any circumstances in which physician assisted suicide is justified, and what would those be?

Then the other question is: In the society with limited resources, which are continually becoming more limited for so called discretionary funds, the kinds of programs you seem to be advocating can only occur if we make choices and, unfortunately, in our society many of these choices are to support the increasing vocal elderly population as compared with young children who really are the future of this country.

How do you see weighing the choices that our society has to make in this serious issue?

DR. HENDIN: Well, let me answer the first question first. Justification is a funny word in this situation. I have often tried to find out what was the movie I saw as a child where somebody is being tortured and burned to death by some tribe of savages, and a friend of his is in the woods in the distance, and to relieve his suffering shoots the fellow so that he dies quickly. It was a movie made from a Cooper novel? Okay. Now you have given me the answer. Thank you.

Now I could give you examples that are more reasonable in life. There are situations where — in combat where somebody is — half their body is shot off, and they are going to die in a few minutes, and you have nothing that you can do, and somebody ends their life because there is no way of relieving that suffering. But in practice, that is not true in virtually any situation that you can think of, if only because of something that some other people mentioned. It's possible to sedate somebody.

Assuming you couldn't relieve the suffering in any other way, yes, I wouldn't — nobody is going to punish you for having done that, whether — so people would feel it was justified. But one doesn't usually make law or policy out of that kind of situation.

With regard to some of the cost issues, the biggest cost issues had to do with keeping people in intensive care units on life support systems that were going to die in days, and the costs of being in intensive care units are enormous compared to anything else.

Palliative care at the end of life is minimal compared to that kind of cost that you have. I think that people now can request to be — not be kept on life support, and that all you are doing is prolonging the dying process. So people have that choice, and most people are comfortable with that choice.

People may be less comfortable if a surrogate makes that choice, but those are issues that we decided we had defined, I think, correctly, we weren't going to get into all the details of that. But those are legitimate concerns.

I think we are already beginning to make certain choices with regard to care. You are not apt to get a heart transplant if you are in your seventies as opposed to somebody younger, and those are choices we are going to have to make.

I don't think the choice of making life comfortable in the last months of life is going to be that
prohibitive, but even if cost is an issue, I would hate to see us not do some of these simple measures that can be done, just because it might be cheaper to end somebody's life.

I think I would rather see society address as a problem the fact that physicians aren't trained to do even simple measures. I mean, there is a case that was published in a book that Leon contributed to in which a lady was in excruciating pain from — she was on medication. She was dying, and the doctor was prepared to end her life, but he called a Dutch doctor who in his own region is a sort of pioneer for palliative care, and that doctor hadn't realized that the medication she was on — she was not too articulate, and she couldn't express herself well — that the medication she was on was causing intolerable constipation, and that was responsible for her abdominal pain. Once he relieved that, the whole situation was different.

So sometimes the measures are relatively simple, but the difference between what palliative care doctors know and what the average physician knows has been enormous up to now. So I think everybody is going to — Oregon may be addressing it in ways that are a little bit too rigid.

You're trying to say for this condition, that this is covered for so much money, this not. I don't know whether that can be done.

It's kind of interesting that they are doing it, because the Dutch have something of the same kind of mentality where they think by regulation you can almost deal with all problems. So that if you are in academic life and you are a professor, you are expected to have so many references in articles you submit to publication. If you are an associate professor, it's less, an assistant professor still less. That sort of has no relationship to the subject.

When Einstein published his first paper, there were no references. So I mean, it doesn't fully make sense, and they do the same thing with regard to the leave you get if somebody dies. They define it whether you get a day, a day and a half and whatever based upon whether it's a parent, a wife. But it's conceivable that somebody who is not your parent or your wife or whatever is closer to you, but they somehow think you can define it in that kind of way.

So Oregon's health care system is unique in the way they are trying to do it, and I think they need a little more flexibility than that in the system. Certainly, the cost is an issue. And as I quoted this Dutch doctor, he felt that the cost was going to be responsible for people just being put to death to avoid the cost, even though he regretted it.

DR. FOSTER: May I just make one comment? One hopeful sign may be in terms of palliative — it's not — What I'm going to speak about is not exactly related to that, but the accreditation of all hospitals now require documentation of relief of pain. You can lose your accreditation from the JCHO if you do not document this.

Now this is usually in acute cases in the hospital. It doesn't have anything to do necessarily with the end of life, but because all house officers now, for example, carry cards with the exact — you know, the dosage and the relative amounts of narcotics that may be needed, it's much easier to relieve pain now and to have information about that than before.

My view is that, because that is necessary in the acute hospital, that when these physicians go out into practice, they have the experience of pain relief that might be applicable under these circumstances. So I think a modest optimism about this issue.

In addition to that, most hospitals now have palliative care teams which the residents rotate through. Now they are not going to be — we can't train everybody to be a world expert in terms of palliative care, but the general principles of presence, of comfort, of talking to patients and so forth with pain relief, I think, are going to be more widely experienced than what you have sort of hinted at here, just because of the fact that you can't have a hospital now if you don't do that.

DR. HENDIN: I think, though, that — I agree with you completely, but the JCHO was persuaded to do that only in the last six or seven years, and the people who are involved in pain — it took a while. But that's where things have changed. That's part of it. We are trying to do the same thing to make the standards include education and ability to deal with depression the same way.

We have been using what happened with the people who got that done in pain as a model for what was done. So we are hoping to be able to do the same thing.

CHAIRMAN KASS: We have run slightly over, but we've actually got Charles and Paul. Maybe, unless there is a dialectic involved, maybe the both of you would make comment, and then Dr. Hendin could respond.
DR. KRAUTHAMMER: No dialectic. Just a simple question. I am encouraged, Dr. Lawler, by your optimism that in 10 or 15 years the truth will out, and the problem may disappear. On this Council, that’s a pretty unusual situation to find ourselves in, where we are generally in the mode of sticking our fingers in the dike and hoping that we are going to hold off things for a year or two or five.

Are there other jurisdictions in the world that might be going toward assisted suicide? In other words, in that intervening 10 or 15 years are we just going to have Oregon and The Netherlands or are there other countries — it’s a factual issue — or states that are looking into or on the threshold of going the way of The Netherlands?

DR. HENDIN: By the way, I may be optimistic by nature. So maybe you need to discount that a little bit. But I do feel that — it isn’t that I don’t think there is danger. I think there is danger if we don’t hold the line and if other states — California is certainly going to be in play right now, and one doesn’t know what will happen, and Vermont is also going to be considering it.

So far whenever the states have looked into it, not only — the more they know, not only have they turned it down. The states that didn’t have laws prohibiting assisted suicide ended up passing them. So since all of this has happened, about nine more states have such laws. But I spent — with Dr. Foley, we spent a week in Hawaii a year ago, and it was very close, and we thought we made a difference, and I see it was defeated again. But California certainly is a danger, and so is Vermont.

With regard to other countries, Belgium recently passed a law permitting assisted suicide over the opposition of the doctors in Belgium, which is exceptional. And it’s a conflict there, because a lot of doctors are just refusing to cooperate with the law, and what will happen we don’t know.

Switzerland has technically always permitted assisted suicide with a law going back to the beginning of the century, and that law was designed for entirely other purposes. But now people are taking advantage of it to try to come to Switzerland and have their lives ended that way, and the Swiss are trying to limit that.

So I wouldn’t say that it is — what was the expression? — a slam dunk. I wouldn’t say it’s a certainty, but I think that, if you keep presenting it to people, that you give them these other choices and that the issue isn’t that you are taking away some right that they have but you are giving them a right that they don’t have, which is essentially what the Supreme Court suggested, or at least five of the Justices subscribe to that they have a right to that end-of-life care.

I think that is the better way to go, and how you frame it seems to have a big deal, a big effect on what eventually happens. So I think there is reason to feel that — I was excited seven, eight years ago when the AMA decided to educate doctors with regard to it, and not that it mattered that the AMA noticed, but I had this dialogue with the President then that I had lapsed my membership for 10 years and I immediately joined just as a personal way of expressing.

I was actually very pleased to be invited here, because just the fact that you are dealing with end-of-life care issues is, to me, a very positive step. We are in our foundation trying to do something, but there are foundations that are doing more than we. We are limited in the direction or dimension we are doing, but we are doing something, and there are others that are doing more.

I think that the more people know about it, that is possible that that will change. Certainly, it has happened in the states. Congressional committees in the states that were absolutely for it — in Maine the polls taken before their vote, before their referendum — and of course, referendum is the way you are going to get this, because the public lags behind in the knowledge.

So I’m not in favor that that is the best way to decide public policy, because slogans are used to decide it, and people aren’t informed. But the Maine Medical Association promised the public that they would do more for palliative care.

I think the best thing we can do is to see to it that a lot of these promises are kept, because sometimes they make these promises out of the fear, and then there is no follow-up on what they do. Then you will lose. If the medical associations don’t stay on top of this in each state, they will lose.

I was afraid of that for Hawaii, that we persuaded them — or they were persuaded themselves that what they needed to concentrate on was end-of-life care, and they promised it to all of their group. I don’t know. I don’t know the facts, but I think the thing you want to do is check up on whether they are following through on those promises.

CHAIRMAN KASS: The last comment to Paul McHugh.
DR. MCHUGH: My friends have noted that I have been pretty unnaturally quiet here today, but that is because I am always your pupil on these matters and have once again been illuminated by what you had to say, and particularly how you responded to the important questions that have been raised by the Council here today, which all have been very interesting to me.

To develop a last question for you, just to hear how you would deal with it, this comes out of my experience over time with this question that has been developed here in the Council, namely, the distinction between the meaningful moods that relate to life circumstances and the disordered moods that you and I know as depression.

So often a confusion of these two things or even the admixture of these two things turn up in clinical situations and are difficult for not only families and people observing from the public but even difficult for doctors and investigators.

My experience with this came in three interestingly similar and distinct areas of neuro-psychiatric research. We at Hopkins were very interested in three conditions, in each one of which a disorder of mood of the kind that we think of as pathological turned up, but couldn’t even get through the NIH, at first, research proposals to study that because in each of these conditions it was believed that the depression was to be expected, even though we had demonstrated that equally disordered physical conditions did not produce depression in other people.

Those three conditions were Huntington’s Disease, cerebral vascular stroke of particular locations, and AIDS — cerebral disorders with AIDS.

In each one of these conditions we saw a very large number of patients who had clearly disturbed reality testing because of their depressive state, and in each one of them we wanted to launch research programs. And every time the first response to our RO1 programs was what are you talking about, this is silly because everybody who has Huntington’s Disease, cerebral vascular stroke or AIDS is to be expected meaningfully distressed. It took a good bit of time showing how these were special.

Now you have made a point that suicide is not simply an outcome of depression. There is not a one to one either that depressed people get — that commit suicide or that the only suicidal things are depressed patients. But you perhaps could tell us whether you think that contemporary neuro-psychiatric research has something ultimately to offer us in relationship to the depressed patients, showing, for example, hypothalamic disorders or things of that sort that go along with the depression that could give those individuals that want a neural basis for their determination, not just the psychological history and mental state that you and I are familiar with to make that distinction for them.

Where are we in relationship to suicidal patients in relationship to the neurochemical, hypothalamic, other mechanisms that could allow us an even stronger place to offer our therapeutic enterprises?

DR. HENDIN: Well, that is a big subject, but let me take at least the most significant example that people seem to be working on today. The experience that we have had is that a lot of people have suicidal ideas, and maybe a majority of the population at some time has thought of suicide, and there are a lot of people who are depressed who are not suicidal.

I was indicating certain conditions that went with it. But probably the trait that has had most scientific documentation and is traceable to brain regions has to do with impulsivity. So that people — Most people will have the thought, “Wouldn’t I be better off dead in this situation?” but they don’t act on it, and impulsive people tend to be people who act on it. But the trait of impulsivity seems to be both biological and genetic, and there’s a lot of work that’s being done on that right now.

Now that’s the one that I’m most familiar with. We get grant applications for it, and one of the advantages of being in my position is I get to see what people are doing research about. So that the research is moving very much in that direction.

CHAIRMAN KASS: Thank you very much, Dr. Hendin, for a wonderful opening, and also thanks for your sterling work in keeping the country as a whole informed of these practices.

We are adjourned. Let’s take 15 minutes. At five after we will start with Joanne Lynn’s presentation.

(Whereupon, the foregoing matter went off the record at 10:47 a.m. and went back on the record at 11:14 a.m.)
CHAIRMAN KASS: Could we get started, please?

Session two of Aging and Caregiving: Long-term Care and New Patterns of Decline. And in this session we go back explicitly to the issues of long-term care that we have been considering for some time. And we're very, very fortunate to have with us Dr. Joanne Lynn, who for more than 25 years has been among the nation's most vigorous physicians, researchers and advocates for proper care for the elderly and dying.

Joanne was actually an Assistant Director for Medical Studies in a previous Presidential Commission on the study of ethical problems in medicine; was for a dozen years the Medical Director of hospice of Washington; has been working as a clinician in the care of elderly and dying patients; and is now the Director of the Washington Home Center for Palliative and Care Studies. She is also a senior researcher of the RAND Corporation at the Center to Improve Care for the Dying, and the co-author of the RAND Report, which you have in your briefing book.

Joanne gave a presentation to the staff, oh it's several months ago I guess, which was really quite eye opening. And for that reason, among many others, we were very eager to get her to come and make a presentation here. And she's, I think, going to be the first physician ever to present to this body who is going to actually talk to us without slides.

So welcome to you, Joanne, and we look forward to your talk.

DR. LYNN: Thank you.

It's a pleasure to be among you. I've certainly worked more on the staff end of these sorts of endeavors than at the table. So I really thought that this would be an opportunity for you to try on some ideas.

I'm very pleased to be in the company of three distinguished thinkers and leaders with well-honed ideas and bodies of work that you will spend the rest of your day with.

I must tell you that at least with regard to the things that I'll be guiding you through, I am something of a junior scholar, having put these things together pretty much in the last decade. These are ideas that have not had the merit of longstanding in the society or a lot of data behind them. They do have the merit of being consistent with all the data, and I think better ideas than we have mostly been working with. But I would expect that one of the things that I'll end up with here is charging you all to carry them forward and keep working on developing them.

One of my themes is that we need better ways to think about the end-of-life and better categories, better language. And to that extent, I've given you just a two-page outline and you have the RAND White Paper. Those of you who want to get into any of these ideas in further detail could use the book Sick To Death And Not Going To Take It Anymore! where these ideas are developed a little further. But to a large extent there isn't a lot out there beyond this, so I'm looking to you to help to do that.

I'm going to walk you through some facts and ideas and then try to save lots of time for discussion of what this Council's role could be in shaping how the United States faces the challenge of large numbers of us coming to the end-of-life and aging at the same time, and having the opportunity to live to old age. That's the first theme.

Do you all have the two-page handout? Okay.

So the first thing that I wanted to take up was just the obvious demographic shift, but I think that there are some facts about it that we mostly dodged and we don't really quite take account of. One is that almost everybody who makes it to 65, makes it to 80 or 85. And that now about 4 out of 5 of us make it to 65. This wasn't true even when Medicare passed. We had lost so many people from the depression and the wars and so forth that even though the life expectancy wasn't a whole lot less, there were just many fewer people who made it into old age. Now almost all of us around the table not only expect to make it into old age, we will feel quite thwarted and unfairly treated if we don't do that. But it means a very different way of coming to the end-of-life.

And if you have a glance at the table on page 2 of the White Paper you'll see the kind of extraordinary shifts that this means. At the turn of the last century, the average woman who made it through infancy died in a complication of childbirth or at least in her middle years. The average man died in the complication of his employment. And we've forgotten just how many people died at work.
The people who escaped those, there were only two major chronic illnesses: tuberculosis and mental illness. We mostly pushed those folks out of the heart of the community into some other setting. So the community was pretty much made up of able bodied people. Dying was quick from the onset to death, was ordinarily very rapid. If you read Osler’s textbook from the turn of the last century, you’ll see the chilling statement that an adult who presents with full blown diabetes will ordinarily be dead within a month. Think of diabetes as an acute illness. You know, it’s just so far beyond us now. But it does mean that we now mostly get to die with very serious chronic illness. And it’s only a very small number of patterns. We basically either have cancer, we have heart or lung disease, a few other organ system failures although numerically they’re much smaller, or we have various combinations of frailty including dementia.

Half of the people who make it to 85 will die with serious cognitive failure as part of their final course. Nineteen out of 20 people who make it to 85 will have serious mobility problems as part of their final course.

The degree to which we are facing large numbers of people with serious disability, we really haven’t really quite come to terms with. The average woman now will have three years of self-care disability. The average man about two. Men don’t live as long and they have somewhat more heart disease. Women live a little longer and have more arthritis, so we end up with a little more disability.

But think about that. That is as long as you spend in preschool. Can you think of any character on television in this phase of life? Any character who has been on TV two weeks in a row? There are two or three counterexamples. They almost all have cancer. There’s essentially nobody with frailty, nobody with stroke, nobody living with this part of one’s life. It’s not been part of our public life, it’s been closeted away, we mostly haven’t talked about it in part because we just don’t even have the stories to tell. We’ve lived with this such a short time that we don’t even know how to raise the issues.

We will have much more disability and we will have much more poverty, even without any changes in Social Security such as now are being contemplated. The fact that woman will live so long with deficient pensions guarantees that we will have the onset of poverty before illness in old age in a way that we have not seen since the depression. At the present time most women become poor at the time they’re in long-term care. I say women because it almost doesn’t matter for men. In our society men marry younger women. The woman takes care of them during their illness. A woman faces an average of seven years of widowhood at an income of just slightly more than half of the shared income the couple would have had.

As we have more and more people with short marriages and more and more men who are unemployed for long periods, we actually have a crisis of pension income. And, again, these are the kinds of things that we just haven’t thought about as part of end-of-life care. What are we going to do with large numbers of our mothers having no way to pay the rent? And in large part because of the wage differentials throughout their life span and because they’re the ones who provide the hands-on care.

Women now provide about a year longer hands-on care to adults than they do to children. It’s already a dominant part of our lives, not a minority part of our lives, and expected to become much more substantial. Men provide care almost entirely to spouses. There’re very few men taking care of their mothers, their cousins, their sisters, their brothers. Women, on the other hand, take care of all those other family relations, not just their spouse.

So family caregiving tends to be an economic reality for women much more than men, which was fine in the Ozzie and Harriet world in which everybody was in a couple and they all stayed together. In a world in which there’s mix and match marriages and in which men are not so reliably employed, it turns out to be disastrous. And disastrous especially to communities of color or communities that have traditionally been impoverished. Because in those arenas the opportunity for spousal attention is really diminished.

So I know this sounds very different than the conversation about physician assisted suicide and sort of rational choices in medical care. But it’s the kind of thing it seems that we have to start uncovering and realizing what we’re up against. Because all of us who are going to be 80 in 20 years are today 60. You know, it’s not an unknown group of people. And we only have a relatively short period of time in which to recreate a society in which you could count on growing old and living comfortably. And right now with no changes, you cannot count on that. Most people will become impoverished. Many will get inadequate medical care. You will not be able to count on being
comfortable or comforted. And yet it’s within our control. I mean, this is a predictable calamity we could readily rally to take steps.

One of the things that we’re really deficient in is stories. I had a wonderful elderly lady who I was making rounds on at Christmas a few years ago. And she was in the hospital. And she was 86. And she said, “You know, Dr. Lynn, I’ve always turned to the Bible in times like this, and the Bible has always shown me a story of how to get through a tough time in my life. But no one in the Bible died like this.”

And I was in a hurry, and you’ll forgive me, but I was not really thinking my theology through and I said, “How about Job?” And she looked at me in that wonderful way 86 year olds have of looking at whippersnappers and said, “Job lived.” And she’s right. There are no stories in the Bible of long-term disability, of people living with a fatal illness for 5 and 10 years knowing that it will take their life, not knowing exactly when, and expecting to get worse and dependent upon the community because you couldn’t live that way in a time in which you had to make it out to the outhouse, you had to build your fire. You know, life was harder and you didn’t have medical care to get you through pneumonias and all those sorts of things.

So we’ve created our trap, but we don’t have any stories of what it is to live well in that circumstance. What is it to be a good husband, a good father, a good mother, a good child in the circumstances of very long-term disability?

We have this sense that we can talk about end-of-life care as if those who are dying are separate from the rest of us as, you know, men from women; there are almost no ambiguous cases. Where if a doctor was just honest, you could tell who was dying. That has to be one of the most pernicious myths going because it has this sense that we could just do just the right thing for the hospice population and we can walk out on long-term care, we can walk out on serious long-term disability and all those sorts of things and just do the right thing for the dying person.

Well, maybe that would turn out to be the case. But we did some work on prognostication and how well we can prognosticate. And, again, this is one of the toughest truths to take to heart. The average person who dies today of heart failure, yesterday had a 50/50 chance to live six months. Heart failure is our biggest single diagnoses in Medicare. The average person who dies today of heart failure, yesterday had a 50/50 chance to live six months. So yesterday they were just barely qualified in a statistical sense for hospice care.

How could that be? I mean, people say that can’t be true. Well, it turns out that the usual way of dying now is to be living on thin ice and to have a rather unpredictable event spell the end. So the person is living with bad heart failure. They can’t climb steps, they can’t get the groceries in, they can’t eat any salt, they’re on all kinds of medications but they’re looking kind of stable. They aren’t looking any worse on Thursday than they were on Wednesday. They’re not a dynamo, they’re not 20-years-old, but they’re getting along. And then they get a pneumonia, they get an arrhythmia, they go off their diet, they run out of their pills or whatever, some calamity happens. And the course to being dead is very fast. But the background was that of serious chronic illness.

So you could say for 100 people with bad heart failure, I can draw you a curve of what the survival span is going to look like. I can be very accurate on that curve. What I can’t tell you is whether Mrs. Jones is going to die early or late. And the idea of unpredictable dying in the context of serious chronic illness is now our dominate way to live out the end-of-life, whereas our dominate myth is sweet young thing — now remember I’m a geriatrician so young is anything under 80 — gets terrible disease, almost always cancer, does something stupid, rails at fate, tears up her family, brings it together, talks with God, dies in her bed, lily on breast, one hour and 45 minutes. You know, it’s convenient for the movies and it’s the only story we know how to tell. It’s Love Story, it’s Steel Magnolias, it’s Tuesdays with Morrie. It’s every story we tell with just a couple of exceptions. It is a minority way to die. Very few people have just 4 to 6 weeks of a real dwindling course at the end and before that they were really doing okay.

Now it’s much more common to live a long time. In many ways the major success of modern medicine is the opportunity to live a long time with a disease that used to be fatal. I mean, I remember when people — when I first was in training, people would come into the hospital all the time with a heart attack and be dead. I mean, they would be dead that day. Now we have almost nobody who makes it to the hospital who dies in front of us. And we have such good revascularization, such good ways of restimulating the heart that they almost all make it out of the hospital that time and have the opportunity to live with serious heart disease on downstream, which is a whole lot better thing to do. I mean, I’m not saying we should all go back on this. It just means we need a different kind of thing for the downstream illness and we haven’t thought that through.
We thought we were doing just such hotshot stuff to save the life up front that we didn’t think we had any obligation to life downstream. And we do, that’s still us. You know, it’s still us in the future of these people with serious long-term illness that will eventually be fatal but will live with a long time.

So it’s a very different image of what it is to come to the st of us will have a very serious disabi
lity for a substantial p We will have a label of an illness that we know to be fatal incluvery old . I mean at some point just frailty catches up a terribly important specific diagnosis. And in a sense we’ll know who won’t know exactly when. And what we need are social arrangements that makes sense of that piece of our liv to live meaningfully and comfortably at a price the community can sustain, a way that we can dish up the right kind of services over and over again, be reliable about it, make sure that the community can sustain that and have it be the kind of thing that patients, that those of us who are going to get old, can rely on.

That’s a very different image of what end-of-life care is than rescuing people from bad pain or just providing hospice care. It means we have to take this phase of our life as a population and figure out things like housing and transportation, and pain management and family support that we ordinarily sort of marginalize out of the health care system.

So my point is that living well with fatal illness is different from what we’ve called dying. I want to just stress that one of the important calamities awaiting us is family caregiving. I’ve mentioned some of the kinds of dysfunctions that face family caregivers. I bet if we went around the table here, how many people on the Council have more than three daughters or daughters-in-law? How many of you have more than three daughters or daughters-in-law? No one? No. One. Very good. Oh, two. Very good. So two of you have a better than 50/50 chance of never needing institutional long-term care.

The rest of us were imprudent enough not to have large families. We also were imprudent enough to shut down much of immigration of the kinds of people who would do this work. In Washington, D.C. here the average nursing home aide or home health aide is so poorly paid that they are on food stamps. It is not plausible that in the future era that can be the economics of direct caregiving. It is very hard work. Almost nobody in the room would do it at a good wage, much less at a wage that doesn’t afford you the opportunity to rent an apartment in Washington. So we face an enormous crisis in direct caregiving.

Who is going to spoon feed us? We didn’t raise enough daughters and we didn’t train our sons.

So family caregivers have very difficult work. Every other country in the world has a family caregiver policy. Most provide income. Virtually all provide inflation index pensions. Virtually all provide health insurance. We provide none of that. We provide no respite care, no training. And as if to make it even harder, we provide no honor so that we do not think of the woman who took off work to take care of a mother as a hero. And we don’t have ordinary patterns in which we reach out to make that person still part of the community and someone of value. We instead just ignore them. It is as if we set out to see how hard we could make family caregiving, and yet half of all the direct care in the country is given for free by families.

So we are going to have to really rethink what we need to do to support family caregiving.

So then there are a couple of other facts there, because one that I wanted to — because the costs came up before. Just have a look at the graph in figure 1 which is on page 3 of the White Paper.

Almost everything we graph in health care, health care costs, uses age as the X axis and Y as costs or hospitalization or something of the sort. A very interesting thing happens if instead you try graphing it from zero to 100 percent of a life span. So a life span of 50 years goes across the whole X axis and so does a life span of 100 years.

It turns out that almost all the costs of health care in your life span are in the last tenth, no matter how long you live. Now obviously there’s some infants and so forth where this starts not behaving well. But for almost all of us if you die at 50 of breast cancer, your biggest expenses will almost all be in your last five years. If you die at 100 of frailty, it will be in your last ten years.

We have concentrated the costs of care and this period of disability so extensively, and yet we don’t see it in the ordinary ways we graph things and look at the facts.

I think once we started seeing this kind of relationship, we’d say oh but wait a minute what are we buying here. And we’d say we aren’t buying what we want. We aren’t buying confidence. We aren’t buying reliability. We aren’t buying symptom management. We aren’t buying good things for our
families. We're buying desperate efforts to correct a physiology in the hopes that it will give us a little longer life. And while that is a good thing to do in general, it may well be a disproportionate cost so that many of my older patients will turn to me and say why is it that I can get any surgery that I want and I can't get Meals on Wheels on a weekend? Why is it that I can get any intensive care unit treatment that I want or now shortly any drug that I want as soon as Medicare Part D comes on board, but I can't get someone to help me with my dentures?

You know, if we looked at the priorities of 88 year old women living alone, we would have built a very different care system. We built a care system around the hopes and fears of 50-year-old men in suits. We did not build a care system around the hopes and fears of 88-year-old ladies desperate with three or four illness and scared about their incomes. And we now have lots and lots of us who are going to be those old ladies, so we need to, I think, rethink where the priorities are in the care system.

So, those are sort of the facts that I wanted to make sure were on the table. But I'll break in here and encourage you to raise any questions of clarification, and then we'll go on to try to build the care system that we want to have.

Anyone?

CHAIRMAN KASS: Janet?

DR. ROWLEY: You may be going to deal with this later on, but what impact is increasing obesity in children and young people on young/ middle aged adults, and the dramatic increase in diabetes; what impact is that going to have on longevity, life expectancy and, of course, again some of these end-of-life issues? But they may happen much earlier than 65. Now you're sort of saying if you make it to 65, you're going to make it to 85. But is this going to change demographics?

DR. LYNN: Yes. And it's a very complicated iteration that we haven't really sorted out terribly well.

On the whole I think the evidence is that the increasing obesity will slightly diminish our life span and greatly increase our disability. That on the whole we will be pretty good at patching up the damaged heart and letting the person live almost as long as they would have lived as a lean and fit person, but they will have much more arthritis and they will have much more muscular conditions, and they will have much more renal failure. And so I think that the disability rate will be expected to go up with a modest diminution of survival time and a bigger increase in the period of time with disability.

The degree to which that actually has an impact in the next 20 years is relatively modest, because most of us have sort of cast our lot by — you know, people who are going to be 80 in 2025 are already old enough that their life span experience with obesity is not going to have much impact. What the impact will be in 2060 is what we need to be worried about right now. But in the short run it isn't going to make much difference.

DR. MCHUGH: Yes. I was fascinated by what you were saying, but I just have one specific question. You have there in figure 1 an interesting graph that talks about America's current health care expenditures over a life span. But you mentioned, of course, that what's happened over time is that our life spans have extended. Would that graph have been any different if it were a 100 years ago? Wouldn't we then also be expending most of our resources on the dying patient?

DR. LYNN: Well, actually, it appears not to be. And I would love to have the opportunity to really delve into the data and see if I could build this up. But if you think about how people came to the end of their lives in 1900 and how they lived their lives, actually health care was a very small piece of your total costs.

DR. MCHUGH: I mean just relative to overall health care services.

DR. LYNN: I understand. But I'm saying on the whole people got sick and died all in one sentence. You know, they were run over by the horse, maybe lived three days. They got appendicitis and died that week. They had diabetes and died in a month. There was very little long-term care. There was very little long-term disability. As I say, except for tuberculosis and mental illness we did not have very much long-term disability in the community. And I mean those weren't in the community, those were put off in other institutions.

At the turn of the century in New York City the average woman died as a complication of child birth. And think how rapid that was. The average man of a complication of his employment.
So I remember growing up in West Virginia where there were lots of my classmates with parents who died in the mines or fathers who died in the mines or fathers who died of black lung disease. And you know dying at 45 with black lung disease was a fairly rapid dying. We don't have very many of those anymore.

So one would guess that the curve was substantially flatter, that there were more of a proportion of your lifetime expenses were scattered throughout as you had an injury or, you know, a complicated childbirth or something of this sort. And that the end of the life didn't add a lot to the costs because there just wasn't much opportunity to throw much at you.

**DR. MCHUGH:** I see. So this is an advantage? This is a positive thing because we are able to do more at this stage.

**DR. LYNN:** Yes, it's more what we are buying with it. I mean, I think fundamentally there are four health care systems that we need to think about: One is reproduction and childbirth. One is the long term in which most of us are reasonably healthy and what we need then is prevention and emergency services. One is this small number of people with long-term disability throughout a normal life span or at least a prolonged life span who need lots and lots of services in order to be enabled to live well, but who are going to need that service all the time. And then there's all of the rest of us who get old and frail and sick and need extensive services to live reasonably well for a relatively short period of time, that is on the order of 3 to 6 years, that during which we are getting sicker with a fatal illness.

And the reason I say the four different kinds of care systems is because there are very different priorities in them. You know, it is really different to be at 92 and have had a stroke and to be frail to have your muscles failing and to feel as if your life has come to completion. And maybe there are important spiritual issues to do or family issues to do, but living a few more months is a nice thing, but it's not a terribly high priority like it is for the 45-year-old guy who has just found he has colon cancer. Well, yes, he has a fatal illness, but his living 3 to 6 more months would be really important for a chance to make things right with his family.

So the kinds of priorities and where we want to put our emphasis I think is different in these different pieces of one's life. As you get to serious chronic long-term illness at the end of life, continuity becomes terribly important and yet we build a care system with "doc in the boxes," you know, where continuity is just not valued. I think that we should probably come to a care system in which a doctor really couldn't provide care for a patient with emphysema unless they're going to be with them through to the end. I mean, that team at least. Not necessarily that individual doctor. But just like we do with obstetrics, you'd have a small team that would stay with the person throughout.

The idea that you can take good care of a patient with emphysema by meeting them in the emergency room for the first time is just silly. Of course it's different to know the person over time to know how they look, to know what their labs have been, to know how their family reacts and what they've got at home. Of course it's different and better. So why do we build "doc in the box" care systems in which there are silos in which we shuttle patients from one to the other and we put no value on continuity? So I think the priorities are a little different.

**CHAIRMAN KASS:** Let's get a couple of short questions, because Joanne I think would like to fill out the rest of the time. So these should be questions I think for information about the facts rather than —

**DR. LYNN:** That's okay. People have to make it their own, so I'll take it.

**CHAIRMAN KASS:** Michael?

**PROF. SANDEL:** This is just about a fact that was very striking that you gave early on. You said that women on average spend a year more caring for the elderly than for children?

**DR. LYNN:** Caring for adults, yes.

**PROF. SANDEL:** For adults.

**DR. LYNN:** Yes.

**PROF. SANDEL:** What is the actual finding?

**DR. LYNN:** It's about 18 years now that the average woman spends taking care of children and it's about 19 years that the average American woman spends taking care of a dependent adult. That
dependent adult, obviously, can be a grown-up child or a spouse who got injured at 32. But numerically the large numbers are people taking care of old people. You know, of people who have their fatal illness and are going to die. So large numbers. And family caregiving has now become — you know, Rosalynn Carter was fond of saying there are only three kinds of people, people who are currently caregivers, people who have been caregivers, and people who will be caregivers. It’s going to be just a dominate part of all of our lives and yet we don’t see ourselves in that role.

People take care of family members for years and years and you say well aren’t there some political issues around family caregiving. And they said do I know anybody who is a family caregiver. Well, you say well wait a minute your mother has been living with you for the last 7 or 8 years. You’ve been getting the groceries in. Well, unless they’re providing kind of diapering, they don’t think of it as caregiving. They think of it as just what families do for each other. And yet the fact that somebody had to leave work and has cut into their retirement income and has greatly altered their social life doesn’t register as being part of a group of people who are spending a lot of time in family caregiving.

Anyway, should I go on. Gil, did you want to—

PROF. MEILAENDER: This was a follow-up on Paul McHugh’s question, though I’m not sure whether I’m going in the same direction Paul was. But there’s a certain tendency to kind of pit the medical system we’ve created against what we need to deal with the kind of problems you’re talking about.

I took Paul’s question to be pointing to the fact, though, that we wouldn’t have these problems if we hadn’t accomplished something good.

DR. LYNN: Oh, yes. Sure.

PROF. MEILAENDER: In other words, as opposed to suggesting that we’ve created something bad, we’ve created something that’s very good in a lot of ways. Then a new set of problems ensues and you have to figure out to do about them.

DR. LYNN: Sure. I would heartily endorse that framing.

PROF. MEILAENDER: Okay.

DR. LYNN: I’ve already had two fatal illnesses in an earlier era. I’m delighted to be alive.

No, I think that this is the kind of problem we should celebrate, but it is a problem. It’s a whole lot better to have automobiles in the city than to have everybody getting around by horseback. Can you imagine the sanitation problem we’d have moving people around by horseback? But it still is a different set of problems and we need to, it seems, to confront the challenges that we’ve created. Maybe it’s better to call them challenges than problems.

I think it’s a very good thing that we mostly get to live long lives. I mean, mostly get to live lives that are valuable and meaningful and comfortable. I think that’s a major triumph of public health and medicine and our lifestyles. But it does carry some challenges that we need to confront.

Let me go on then to there are some better arrangements. Many of you will be familiar with hospice, PACE, the programs of all inclusive care of the elderly.

In some managed care plans I think there are some extraordinary models being developed. I’m especially fond of Kaiser in the west where there are areas where their penetration is so high that they can afford to serve the community rather than being worried about adverse selection of disproportionate pulling in very sick people. And, you know, so you have to get to the point of managed care where you have a lot of people in the community in that in order to be able to provide optimal services.

The VA I think has really stepped out in front. The Veterans Administration now has care in every hospital. They’re the major trainer of doctors, nurses and social workers in care programs. They’ve greatly moved from an institutional-based care to much home- and community-based care. So they try to think through how a whole system would look for a group of veterans.

So we have some interesting models out there. Why can’t we get to really good care? Well, the first thing is we have to have an image of what it is. And you’ll see in the White Paper a figure that sort of outlines these. But the important element here is not the specifics of the things I’ve listed, but the reliability; that the care system would get good enough that you didn’t think you were on the roulette
wheel and that your family might be nailed or you might be bankrupted or your doctor might not come through with good pain management but that you could count on good care.

Many of us are old enough to remember when obstetrics was something of a roulette, or worse and there was really quite a revolution of women saying we are simply going to put up with being schnookered to deliver and meeting the baby sometime later and having no support for breast feeding and all those things. We’re going to take it back in our hands and it was the “our body ourselves” movement and so on. And we really have changed how obstetrics care is provided. But the change is not that women still have to run that gambit. The change is that if you showed up and said not a word you know, and I think I’m pregnant, you’d get just about the right care. I mean the extraordinary revolution in obstetrics is you no longer have to fight for what you want to have happen because obstetricians have said — and the whole obstetric delivery system has said here’s what really makes sense in good obstetrics care. And that’s what we’re basically going to offer. And the woman who shows up and wants something a little different, sure we’ll make room for some differences, but fundamentally we’re going to expect that people want decent pain management and good bonding with the baby and the significant other to be taken care of. You know, there’s a set of things that count.

Well, in end-of-life care what are the set of things that count and could we build a care system that would be reliable in making those available? So the family caregivers were supported. So you’re never in terrible pain. So that the effects upon family finances would be accounted for. You know, could we build a care system in which early in the course of illness a doctor or a nurse or whoever could sit down with a patient and say it’s very unfortunate that you face serious heart disease or lung cancer, or whatever it is that is your particular burden, but at the very least your care system can be counted on to do the following things? We’ve thought these through, we know they work. You cannot be in a setting in our community that won’t be good at managing pain. You can’t be in a setting where you couldn’t get sedation at the end of life. You won’t be in a setting where your family won’t be honored and taken care of. Because we’ve thought this through and we’ve put together a care system that works. That’s what we need. We need the revolution that makes it reliable so that people can stop worrying about the fumbles and errors in the care system and live their life that’s left. And we’re going to live years in this shadow of heart failure. If what matters is that you get to write the great American novel or go fishing, you need to be enabled to go do those things; you know, figure out how to get the oxygen down to the river bank, and get medical care out of center stage.

It’s not primarily about medical care. It’s primarily about the life to live. But that’s a set of stories we don’t know how to tell. We know how to bring the story to life on ER, but we don’t have sitcoms about people who are living with fatal illness. I keep waiting for Golden Girls to come back. I want Maude in a wheelchair from a stroke and now facing some other fatal illness, you know renal failure or something, cracking jokes about sex, being just as irreverent as ever, being quite a character and being realistic about the fact that she’s going to die with this illness and that she’s not going to be out of her wheelchair and she’s going to get sicker, and that’s okay. It’s still wonderful to be 88 years old and living this way and being among friends and having a life that would be valued.

We need to have that sense that you can drop your guard and live your life rather than being worried that the care system is going to end up hurting you. How could we get to that?

Well, it seems at first blush as if it’s just hopelessly complicated. Everybody comes with their own family array and their values, and their different physiologies and their different panoply of illnesses. How could you build a care system that would work?

Well, one of the most important ideas you’ll see on page 8 of the White Paper is that first we have to think about the piece of time when you are very sick with a fatal illness as being worthy of a different kind of care system, and it would have characteristics like continuity, like being responsive to a number of human concerns. And then it turns out that there are roughly three major trajectories. That if we could build a care system that would work for each of these three, we would leave very few people out. That’s a very powerful idea in thinking about how to organize care.

The first is the classic Love Story scenario where the person, you’ll see the Y axis here is sort of doing well versus doing poorly and the X axis is time.

The person goes along really doing pretty well. They may have a terrible diagnosis. But they’re still taking care of themselves, they’re still in their apartment or their house, they’re still seeing the grandchildren, they’re still taking care of their ordinary life activities until finally the illness becomes overwhelming and they take to bed and do badly, and in a sense kind of die on time. This is the classic course with colon cancer, lung cancer, certain kinds of AIDS goes this route. Not very many
other illnesses. But where there's a piece of time where you really could see the person is now dying. They're really fading now. There's less energy this week than they had less week. They're losing week. And this was the model behind hospice. So you can see how you could put together good medical services, good supportive services and then good hospice care, integrate them better and you could serve this population pretty well. Unfortunately for planners, it's only about 20 percent of us who have a course anything like this.

Slightly more of us have a course like the second one where you go along with substantial limitations and intermittent terrible exacerbations. Heart failure, emphysema. You go into the emergency room terribly sick and we're so good at rescuing you that the person after a couple of rounds of this thinks that this is just going to go on forever. They're waiting for cancer. And the doctors don't ever quite get around to saying this illness will kill you just as surely as cancer, but your dying will be sudden. You're dying will be within, at most, a few days of your fatal set of complications.

So we should always have a standby plan for what we're going to do when this illness becomes overwhelming. Do you want to be on a ventilator? Do you want to be in intensive care? Do you want to be at home? Do you want to have a trial of treatment with aggressive treatment and then if it seems as though we've really lost ground, to have those withdrawn? Let's have the plans in place. So you want to limit the rate of exacerbations, improve the life between exacerbation and then always have a plan for the set of exacerbations that's going to take the life.

And so you can see how you could put that together also, but it's a different rhythm, a different set of services than the first one.

Already most of us face the third trajectory. Already it's long-term progressive disability. We can label it as heart failure, we can label it as stroke, we can label it as dementia, we can label it as frailty and old age. But fundamentally, it's inability to take care of one's self on an everyday basis from a set of conditions that are progressive. It will get worse and worse over time, not necessarily on an every week basis but that in six months from now you're very likely to be in worse condition than you are today.

Here it's much more family caregiving, hands-on caregiving, endurance. Can you manage just to stay with the person, honor their existence, support their family for what turns out to be years and years?

To the extent that we are good at delaying onset or preventing cancer and heart disease, we will have more of us traversing this course. This is the most challenging. We don't know how to ascribe — really how to talk about this course yet, to acknowledge that it's fatal, to acknowledge that on the whole we don't have ways of turning around frailty and we aren't likely to. What would we substitute? There's not sort of an easy illness to substitute. But nevertheless, you can see how the kinds of services would be different here.

There would be a lot of family caregiver support. Very good nursing home care when you must use nursing homes. Always having a plan for how to handle the final complications. You can see, though, how the rhythm of the services, the kind of people providing them are going to be somewhat different.

There are now cities in Sweden that are using these models in city planning for paradigmatic cases. They call them the three Esthers: Esther with colon cancer, Esther with heart failure and Esther with dementia. And the idea is that if any Esther in my city can count on good care, then almost everybody can count on good care. It's a powerful idea. It's like that of revolution in obstetrics where you say well if this is the kind of thing you face, let's have a set of services, know how to interdigitate them, know how to support them so that you can count on this level of care.

It's a very powerful idea it seems in organizing how we could think about good end-of-life care. And so that's sort of the core of the pitch here. How we would get from here to there, I've given you a short list. I think we need a political force in the family caregivers. We need to aggressively change our language and stop talking about saving lives and stop talking about how devices and so forth are all, you know, these wondrous things because they save lives. But instead talking about how we're going to live well with the illness that will take our lives.

We need to tell stories. We need to try them on, figure out what it is we're going to learn to value in family behavior, in our own behavior. They're taking every last opportunity to live a little longer or being willing to cut short that kind of pursuit.

We need to try out substantial reforms in demonstration mode. We have done almost nothing of this. We have been so high bound that we just aren't willing to let people try out very dramatically different ways of organizing care.
We need to do quality improvement work in existing programs so that we learn how to make sure we can provide the things that matter.

And then we need to make success and failure visible. We need to be monitoring this on a population basis. You do not know today whether Washington's doing better than Baltimore, or for that matter whether Washington's doing better than they were five years ago because we don't think about this as an epidemiologic issue. And I think that would be an easy thing.

So these are things I think that would be really strong as a national endeavor, and then we can turn to what I think the Council could do. But first I know Dr. Rowley and maybe some others have some comments or questions.

**DR. ROWLEY:** In your diagram that you have here on page 8 you told us that the top figure or top part of the figure included about 20 percent of individuals. Could you give us some data for the middle and the bottom part?

**DR. LYNN:** Yes. These are very rough estimates. But on the order of 20 percent for the top and maybe 25 percent for the middle and then the bottom one gets 40 or 45 percent.

There are only now about 6 percent of people — this is Medicare data on the rates, which is not far off because 83 percent of us now die on Medicare. But there are only 6 percent of people who appear to die suddenly in Medicare. Probably half of them are in the VA, so their expense stream doesn’t exist in Medicare. So one of the things that people have to really come to understand is that it is now very uncommon to die without a substantial prior illness. So we're basically sorting among major illnesses.

**DR. ROWLEY:** Thank you.

**CHAIRMAN KASS:** Gil Meilaender?

**PROF. MEILAENDER:** Could you just give me an example of the sort of thing you might have in mind when you refer to a substantial reform in demonstration mode? What sort of thing might we try out that you say we're just not doing?

**DR. LYNN:** Well, I've got my favorite dozen. We've been trying for the last five years here in Washington to put in place a program, it would be under a Medicaid waiver, a medically complex program. And this would be once a person was at a certain stage of serious illness, and we've got them all outlined, and they had a provider of care that was a team provider who could answer the phone and access the patient's records, could get to the home within an hour day or night, could take care of the person in the hospital, the nursing home, home care, hospice, you know, so they're a continuity provider. Then Medicaid would pay the provider on the order of about $8,000 extra per year. I mean it's a complicated formula, but it basically ends up that on top of fee for service billing. But in return, obviously what they're doing is mobilizing excellent care to where the person lives, lots of family support, always being in touch with somebody who knows you and has your record.

And it turns out that by our estimates we would save in the first 100 patient years, that's first 100 people in the program for a year, we would save Medicaid three-quarters of a million dollars and Medicare three-quarters of a million dollars. What's in the way of doing this? And this is a win all the way around. The patients get better care, everybody saves money.

There are so many forces that keep that from happening. You know, it requires a whole different way of thinking about what is going to be quality care and how you're going to pay for it, and how you're going to regulate it, and who is going to be eligible to play the game. It's not every doctor who can get into this. It's going to have be people who are committed to a very different model of care.

And those are the kinds of things that have been very hard to get implemented. You can't do it on a randomized basis. Every demonstration that Medicare has put in place for the last probably ten years has required randomization at the patient level. You cannot do this kind of change and randomize patient-to-patient. You know, every patient in a particular environment has to be eligible for the program or you can't change how people think.

You know, instead of a person as soon as they run a fever call 911 and send them to the hospital. Instead you have to be thinking, no, actually we mobilize the nurse practitioner out to see them where they are and see if they really have to come into the hospital or if we can take care of them well right where they are. But you can't do that if you're doing it differently for Mrs. Smith and Mrs. Jones in the same doctor's practice.
So we have a thousand influences that make it hard to do these demonstrations. We need a sort of an energy in this, a sort of willingness to let people try things out with protections for the patients. I mean, I don’t think that in anyway we want to put ourselves, after all it’s us in the future that are going to be the patients in these schemes. But more to be willing to take bigger bites of what kinds of things would be possible.

The risk adjustments that we put in place in Medicare so that managed care plans could offer these things are so paltry as to be laughable. You can’t put excellent care into this community on a managed care basis because everybody who’s sick in the community would come to the managed care program and it would be belly-up after the first 100 people that signed up. You have to have a risk adjustment that’s much more robust.

We’re talking about in a D.C. proposal, we’re talking about targeting patients who cost $35,000 a year to Medicare and an equal amount to Medicaid, or even more in some cases. So these are $70,000 a year lives, you know, just on an economic basis. The risk adjustments now available in reimbursing managed care organizations don’t get anywhere close to that level. So we need to be willing to develop the fortitude to try some things out in bigger ways, in communities that are willing to try them out. You know, it might be geographic communities, it might be communities of concern in other ways. But those are the kinds of things I’m thinking of.

I think that we should also try some sort of radical shaking the world up kind of proposals. Like the second time a person comes back to the same hospital with the same serious chronic illness and there’s been no discussion of advanced planning, nothing is documented from the first hospitalization or the time between, then I think the hospital should take a major blow for their reimbursement on this second hospitalization as payment for their error the first time. I mean, they blew it, you know, so they ought to pay for it. I think it would take about a day before that became a priority, you know. This is not hard to do. It’s just that we’ve been willing to tolerate widespread error.

How is it possible that the usual person coming to a hospital in this city today from a nursing home has no advanced care plan? In Oregon now, it’s about 80 or 90 percent. Why can’t we achieve the rates that are achieved in Oregon? Because we’re use to tolerating error. And so we have to find ways, I think, to pull individual sort of examples like that out of the murk and make them poster children for change.

And then we also need to figure out how to change the capacity of the care system and the reimbursement kind of bit-by-bit, you know 20 small steps, to get to a way in which very good providers doing very good jobs can make a living without having induced major disruptions in the care system in the process of reform. And that’s going to take some creative work, but first it takes a will. First it takes a drive of a body like this that would say we ought to get there. We ought not to be the most developed country that’s simply blowing money and blowing resources on irrelevant things and failing to provide the ones that count. We ought to learn how to realign our priorities.

You know, this didn’t come down off the mountain with Moses. You know, this is a human creation from the last 50 years. We can recreate it to match the population we now have.

So that’s the kind of thing I have in mind.

CHAIRMAN KASS: Rebecca Dresser?

PROF. DRESSER: I just want to push you to get to your last part because just for a background, and you may have heard, one of our struggles — we’ve had I think two major struggles with this report. One is how to organize it and what to cover. The other is what can we as a bioethics council add. We’re not a council of health policy makers or economists and we don’t have that expertise. So what can we do? And I guess just looking at this list I see related points, but I wonder if you could incorporate this point into your presentation.

What frustrates me is the lack of political and social appreciation for the seriousness of the problem. And I know as an advocate throughout your life I’m sure you’ve had that frustration a hundred times more. So have you thought about a specifically ethical argument to make about why the current situation is disturbing, wrong, morally inappropriate and so forth that might help us to frame our report?

DR. LYNN: I certainly can try. I mean, the experience of being on the staff of a similar group some years ago at least leads me to trying to figure out some of the things that you might do. I’ve actually added a ninth one while thinking on this since I wrote this up, but let me just run down these a little bit.
I think that in direct answer to Rebecca's comment, I'm not sure that there are the kind of ethics issue that we thought constituted medical ethics 20 years ago. I think it's much more questions of values, questions of what stories are we willing to tell, what myths are we willing to promulgate, what categories are we willing to use, what serves us best. It's not as much the ethical dilemma, you know to stop or not stop a feeding tube or something of this sort. It's much more what kind of people do we want to be. And when we look kind of deeper than we usually look at what we value in our community and in our heritage, how does that speak to us in creating the social arrangements of the future?

And that actually brings us to the point of the one that I added on that isn't written on here yet, which is I think one of the most fundamental challenges, is whether we are largely facing these issues one-by-one or at most in tiny communities, in families or are these largely shared issues? You know, no matter what we could say about your virtues and wealth during the middle of your life, when you come up against it at the end and you're facing mortality, is the commonality among us what speaks to us or is it sort of what you deserve? Fundamentally are we willing to let old ladies die in ditches? Are we willing to walk out on one another in serious illness and old age in a way that we haven't been in the last 60 or 70 years?

When we face enormous numbers of people who are quite dependent and impoverished, are we going to learn to have it be their own problem in the way that we commonly do for homeless men at 45 or are we going to instead say no, actually, this one's a community problem? This one's one we've got to solve altogether.

And I think that's a real problem area in our society at the present time. To what degree are we all another's keepers and obliged to at least work out housing, food, decent care, skin care which turns out to be, contrary to Herb's claim last time, by far the most expensive part.

The ICU, yes, the ICU is more expensive on a per-day basis. But survival is what's expensive at the end-of-life. So you can't really sort of duck out on this by saying, oh well we'll cover ICU care but we won't cover long-term care. I mean, it is the long-term services that really amount to the biggest community commitment. And so we're going to have to at some point bite that bullet.

So to the extent that this Council could bring to bear observations from our literature, observations from the sources we turn to in theology, in grand myths, in the way we think about ourselves; what kind of nation do we want to be? Do we want to be a nation in which if you lived the life in which you didn't save enough, you will face a grim old age or do we want to be the kind of society in which we say well, you know, there's going to be a limit to how grim that can be? We really are going to see to it that people can be fed and clothed and housed and not in terrible pain and their families supported. We're going to share that burden, at least at that point.

So that I think is the kind of thing that you could speak to, not necessarily with a conclusion, but just what kind of sources can we draw from, what kinds of activities could we undertake to help guide us into a better future rather than a more thoughtless future that one that we kind of arrived at willy-nilly without having particularly thought it through.

So that gets back, I guess, to the first one: Draw upon our heritage to find the metaphors and stories that would help grant meaning and language to the challenges of serious disability before death, of caregiver burden and personal growth. You know, what kinds of things are we going to come to value in caregiving?

And I think the most complicated one is how we're going to come to understand and value lives afflicted with serious and progressive dementia. In what way can we come to express a love and comradeship with people who can no longer, in many cases, even acknowledge us? We've written a lot on this sort of thing. But, you know, that's not in common parlance. We don't know how to even talk about these things. Go look at the news stories on Ronald Reagan and see just how little was ever said about what the lived experience is of coming to the end of life with dementia.

Give us more historical perspective on how we're changing. I mean, I've given you one view. It's certainly not the only view, and it may not even be a correct view, but it's also something we don't spend much time on. We don't think about who it is we are becoming and what kinds of histories we could call on.

I think we must give voice to the serious concerns for grinding poverty in old age. We have mostly been spared that. We have very little poverty in old age that the person is not impoverished at the time they enter old age or becomes impoverished because of illness. And we really do have the likelihood of large numbers of women and virtually all women of color who have spent their lives in
poverty who will be in poverty before becoming ill in old age within the next 15 or 20 years. What will that mean to us as a community when we can’t just say well Medicaid will pick it up in a nursing home? Because the person’s actually still quite capable but has no way of making a living, no way of paying the rent.

Provide images of value for caregiving, paid and volunteer caregiving. You know, shall we make heros of the family caregiver? Shall we find ways to reach out and keep those folks involved in a community life or is this just a cross you must bear in silence and we don’t particularly want to hear about it?

Likewise for paid caregivers. You know, paid caregivers are treated as the lowest level of labor. They ordinarily have no disability insurance, no health insurance. They have no union rights, they have no severance pay. They have very little training. They are treated, you know, right in there with migrant workers. And is that the way we want to think about the people who are going to take care of us when we need help with our toothbrushing?

We need to reach out for community support of the frail persons and the caregivers.

We need to find ways to discuss accepting dying, resisting dying, treating symptoms when gains are small and other culturally loaded topics so that our political leaders or people who speak in public don’t just get nailed with anything they say. You know, I hear over and over again in this town how you just can’t talk about that. You say, yes, but if you can’t talk about you can’t ever solve it. You can’t ever come to better solutions.

All of our economics work in health care policy presumes just as a matter of the woodwork that the person would have lived just as long with or without this intervention. As soon as you get to end-of-life care you realize that the biggest variable in play is how long the person lives and we are barred from even talking about it. We count Medicare on cost per hospitalization, cost per month, cost per year; not that it actually affects how long you live. And that interplay of how long one lives and what the experience is like has just been a third rail of public communication.

Again, I don’t have easy answers to this. I’m calling on you as a body that can take on tough issues and help us see what the array of possibilities are, not necessarily to say here’s the one right way of going at it.

I think we need to call for more leadership from political and other public figures. Two weeks ago an article came out saying that influenza immunization might not save lives. The CDC very promptly issued a whole bunch of press releases saying immunizations saves lives. Well, my point would be why don’t we say "delays dying"? Why don’t we say what it really is doing? I mean, we’re talking about people 80 and up living in nursing homes. Saving lives is a metaphor drawn from the polio epidemics. It is a prolongation of life and it might be a very good thing. But it is a very different thing to spread out the mortality curve across a year by reducing the rate at which people die of influenza in a concentrated way as compared to saving lives for some robust other existence.

Our language is so disappointing in regard to these sorts of things. We need a serious investment, it seems, in demonstrations, innovations, data, monitoring how the population does, epidemiology. We are working on such thin data. I mean, the things I presented to you here, not a single fact that I’m relying on has more than one or two studies behind it. We have just not invested in this.

We should go to the National Heart, Lung and Blood Institute as the Institute of Medicine did a few years ago and ask the NIH agencies what they were doing in end-of-life care. National Heart, Lung and Blood came back with that is not in our mandate. That’s the illness that kills a third of us: It is not in their mandate.

The National Institute on Aging talks about healthy aging and prolonging life. Well, by damn, I’m going to die old and my National Institute on Aging ought to be doing research on how I can live well in the shadow of my dying. And we just simply haven’t invested there.

So we could speak to those sorts of things from this base. And we could encourage consideration of these kinds of issues rather than just allowing ourselves to be pulled off in these terribly alluring debates over Terry Schiavo or physician assisted suicide, or any of these sort of numerically smaller issues. They can be symbolically terribly important. I don’t mean you shouldn’t address them. But you shouldn’t only address them. You should call people to really focus on the issues that matter to lots and lots of people. And, yes, of course also talk about physician assisted suicide and also talk about euthanasia and also talk about Terry Schiavo and so forth, but I would want the core of your report to speak to how the usual one among us is going to come into old age and serious age and have at least a decent shot of being in a care system, being in a social system, being in a community
in which you can count on living meaningfully and comfortably right through to the end-of-life at a
cost the community can sustain. And that is quite a challenge and we’ve only got about 15 years to
get it right. If we don’t get it right within the next 15 or 20 years, we are going to learn to walk out on
one another. We’re going to have such widespread poverty, so many people sick at the same time
that we’re going to learn to turn our eyes.

We’ve got this little piece of time here where we could innovate, learn, build a better care system,
built the stories, try things on. And if we don’t use it well, we’ll reap the harvest of our own
insecurities. And those of us who are now still young enough to face old age in 15 or 20 years will get
the benefit of our having dodged the tough question, which is that we’ll have the care system that we
have now or worse. And that’s not enough. So that’s what I want you all to do.

CHAIRMAN KASS: Thank you very much, Joanne.

Let’s open up for general discussion and we’ll take another 10 or 15 minutes.

Dan Foster?

DR. FOSTER: I think that no one would argue that the issues that you address need to be
addressed and are very frightening. You used a phrase a little bit about Washington, but it may be
for the larger society that nobody wants to talk about this. And it’s a multiple problem. I’m not an
economist or a sociologist and I may be saying things wrong, but we really have two countries. You
know, we have sort of a third world country which is really at very great risk and then we have a
developed country which has high life expectancy and all those things and is pretty satisfied with the
way things are.

I used to run a program on the streets of Dallas for the poor. the concept of delayed gain was just,
you know, I’ll give you a quarter I’ll wait to Saturday I’ll give you a dollar. And the kids take the
quarter now because they didn’t know if they were going to have it that time or not. But it’s not just street
kids that do this. If you look at American business, you know, there used to be all this discussion
about well we ought to plan and do research for what the company’s going to do five years down the
line. But CEOs get killed if their stock drops, you know, they know that they ought to be doing this
but it drops.

So the question I’m really wanting to ask here is do you think that in a large country like our own as
opposed to let’s say a small country like Sweden or so forth, is there any sense of getting a consensus
for long-term planning when it seems like everything is determined like the street kid who will take
the quarter now rather than the dollar later? And I’m convinced. We’ve been struggling with how to
get a system of medical care for a very long time. And so I’m wondering — I mean, the Council — the
plans would be sort of a universal plan just like your plan in Washington for complex care. It would
save $750,000 the first 100 year life for Medicare and Medicaid. But to get that through, is that more
reasonable than to try to say let’s take a section of the problem and try to address it rather than sort
of a universal dream? I’m not saying one way or the other. But I’m saying I’m quite skeptical that in
the place where I live, and I’m sure it’s true everywhere else, there are these huge houses being built
and so forth and people who have the money to do that, and I don’t think they’re going to be really
caring about Mrs. So-and-so from the third world or even at the end of their life. So is this realistic
or should we focus more on trying to settle one or two or three small problems even though we ought
to be planning 2040 for all of these things? I mean, that’s a long question, but it’s the realism of the
idea that you can change society by saying this is a moral or ethical and economic and common
sense way to do it. I mean, I’m just not sure that society in a large country of different things it’s
going to be possible to do. I doubt that the Congress or anybody else, or the President or anybody
else is going to buy into that.

DR. LYNN: Yes, it certainly is possible to sort of throw up one’s hands and expect the worse. I
guess as a long time practitioner among those who are sick and dying, I’ve been blessed with an
eternal optimism. You know, if all that list of the arguments we’re giving, you know economic and
social and moral and so forth isn’t enough to move us, then we really are doomed.

There aren’t many other forums in which these issues can have a voice right now. They’re not going
to come up in Congress, you know. They aren’t going to come up in the business environments that
you speak of. So this is one that really could say, you know, think about these framings, think about
these alternative framings, think about the kinds of data you could bring to bear. You know, why
don’t we have a Labor Department report on family caregiving? Why don’t we have a Labor
Department report on paid caregiving? You know, we simply have shown the light in that corner.

You know, I don’t think that you can go from here to some very good reliable, efficient care system in
one swoop. I think it’s going to be a whole lot of small steps. No matter how we think about it it’s going to be a lot of small steps. But either we can make a whole lot of small steps and have some shot of getting there or we could say it’s just never politically convenient, it’s never expedient. You know, we’re going to take the issue of the day and not see how it really adds up.

The Medicare debates last year made a blank check for the drug companies. The Medicare coverage decisions make a blank check for device manufacturers. I want to see the first time we make a blank check for Meals on Wheels. I mean, you know we just have our priorities so out of kilter with this population. And who can speak to that? It seems that this is the kind of place that could at least try to find the sort of cultural spots where we could find some traction.

And I don’t have a nice simple, you know, here’s the roadmap to nirvana. You know, it's much more couldn’t we start finding the points of leverage, and they aren’t going to be in physician assisted suicide and they aren’t going to be in something like that that's largely a highly emotional, personal commitment issue.

The points of leverage for the kinds of change I see are things like the financial issues, the effects upon families, the realistic characterization of what we face in terms of disability farther out. You know, almost everything we can do for preventing serious illness increases disability because it gives you the chance to live into old age, which I think is a good thing. I mean, as you were saying it’s a good thing to get the chance to live into old age. But we should then be figuring out how we’re going to have housing codes that don’t let us build bathrooms that don’t have handrails. I mean it’s a thousand simple things that we need to put in place in order to live well when we have a large proportion of the population very sick at the same time.

So could we get there? There are a couple of things that work in our favor for reform. One is that disparities of the sort that you describe in your work in Dallas actually become less in old age and in serious illness. It’s a very interesting, and I think rather wonderful fact, that we spend almost as much as a community on the rich and the poor at the end-of-life. The last year of life has almost no disparities. There’s some disparities on exactly which services, but there aren’t disparities on the aggregate — or not big ones, on the aggregate investment because the need is so overwhelming. You know, at the time that people are sick enough to die we actually do rally and support one another. At this time we might lose that, but we right now do. That’s a leg up, and so is the fact that all of us face it. It’s never somebody's minority problem. It’s our problem. It’s my mother’s problem. It’s your problem after she’s gone.

So the fact that we are in a sense all in it together maybe gives us a point of political leverage. I’m not sure if that’ll be enough. But, you know, when casting about desperately for a lifeboat, you know, I can find a few that might get us somewhere.

DR. FOSTER: Listen, I’m 100 percent in favor of everything you say. But, you know, you could do what you’re going to do if you let’s say don’t have to spend billions of dollars in a war, for example, and you got the medical care at 16 percent. I just don’t believe the political system at this moment is such that you can do the whole thing. So I’m much more in favor of trying to say, well, what would be some — I don’t want to say this over and over again.

DR. LYNN: But our cultural —

DR. FOSTER: But I think that if we could come and say if we did these three things now, that this would help a whole lot whereas for 2020 we need to do something much more.

One of the things that I think I’ve learned in medicine and everything else, if you have too gigantic a thing, then everybody throws up their hands and says well I believe what she’s saying and I really want that to happen, but it’s not going to happen. So it’s much more helpful to get, let’s say if you got a problem in your community, to get an ambulance system that works than to say well we’ve got to have good care for everybody who is there.

So all I’m asking for is if you could help advise us in terms of priorities of what you say that might be accomplishable in the shortrun while we try to look forward to the things. That’s all I’m trying to say.

DR. LYNN: But we need to set, it seems, both the structures that give us the possibility for that long-term planning. Why don’t we set up somebody? The Institute the Medicine or somewhere that is responsible for trying to lay out the 20 year plan, you know. But then in addition nurture the things that are happening right under our noses.

Medicare has come out with a whole set of quality criteria for hospitals. They have come out with a
set of quality criteria for nursing homes. They may not be perfect, but they are the kind of small
ting. You know, could we get the rate of restraints in nursing homes down to effectively zero?
Could we get the rate of pressure ulcers down to some tiny, tiny number? You know, those are sort
of the low hanging fruit. Could you go after some of those things while working toward — can we
find a way to keep family caregivers from being utterly impoverished in old age, which agrees with
you is a much more intractable problem. But can we try to do both, the planning ahead and setting
up some ways in which the society can hear about the bigger changes that we might want to
contemplate while also making the small steps we can make this year? And it seems that any kind of
intelligent reform is going to have to do both. We're going to have to figure out how to change how
the money runs, how the human resources run and are developed and also set some standards,
declare some errors, you know create some priorities.

You know, effectively last year or two years ago now when Congress passed the Prescription Drug
bill, they inarticulately stated that we're going to have a priority in a blank check approach to
prescription drugs. So a $30,000 drug is going to be covered, and we have many of them coming on
line. There's no similar statement about the prevention of pressure ulcers. You know, a person does
not have a right to a pressure reducing mattress because they can't get out of bed.

And so we're saying things as we move along about our priorities, we just need to maybe call them
into question. Surely it is more important in a nursing home to have pressure relieving mattresses
than to have cholesterol reducing drugs. And yet within a year I'm going to have free access to
cholesterol reducing drugs and not free access to pressure reducing mattresses.

There are many such examples we need to bring to bear and have people debating them and find the
ways in which they can grab the public imagination. That's why I think we need to have the Golden
Girls out there talking about what it is to live in a wheelchair or to face dying with a fatal illness.
Because those are the kinds of things that people can try on and figure out — well, is that how my
family would react? Is that is how I would want them to react? And make a whole lot of small steps.

And again, it might not work. I might come to old age and realize that it's all been for naught and we
have only the inadequacies of the care system exploded by further investment in devices and drugs
and medical treatment and perpetual under-investment in hands on care that we were inadequate to
alter. But if we do that, I do think we'll learn to walk out on one another. We will learn how to let
old ladies be homeless.

CHAIRMAN KASS: The hour is late. There are three people in the queue. And let me ask that the
three make their questions short or comments and then we'll let Joanne just finish as a comment.
Hold off on responding. We'll just get brief comments from Gil, Peter and Ben. Let me ask you be
brief with them.

PROF. MEILAENDER: I'm just going to pass. It would follow up on Dan's, and I think we've
taken it as far as we need to take it right now.

CHAIRMAN KASS: Okay. Peter?

DR. LAWER: Our first speaker this morning got me all optimistic, which was truly out of
character. But you have described what you said is a predictable calamity and you're frustrated
because we can predict what's going to happen, but despite your best efforts as Dan pointed out we
probably won't be able to stop it all that well because here's the problem very quickly. We live in a
society which due to our great medical success more and more people will die of chronic illness or
require a large amount of caregiving at the end-of-life. Meanwhile, this same society is eroding the
reliable foundations of caregiving, which are two. One's the family, and the other is people willing to
work for subsistent wages in a job we don't value all that much because we kind of regard it as
merely custodial that any fool could do. So, given this, given that there's a broader cultural problem
here, answer one of these two questions because we don't have much time.

One, when President Bush gives his next State of the Union on the ownership society, how would
you work this stuff in? Or, number two, what kind of compelling narrative about honor would move
Americans in terms of caregiving? Pick your favorite.

CHAIRMAN KASS: Let's get Ben's comment and then, Joanne, you're not obliged to write the
next State of the Union.

DR. CARSON: Well, I very much sympathize with everything you've been saying, and obviously
they're issues that concern us all and the lack of conversation about it. And I very much understand
the pragmatic point that Dan Foster is making also.
But I wonder if you think it would be possible maybe to bring these things — because we are a crisis-oriented society and we only do things when it’s a crisis — to advocate maybe a partial solution such as a government pay for catastrophic health care which would then force us to examine issues which we neglect at this point?

**DR. LYNN:** I'll take up Dr. Carson's comment first, I think.

I guess I am perpetually humbled by how little I know and how unpredictable major policy shifts end up being. So maybe catastrophic coverage, especially if it covered long-term care as well, is the right direction to go. And, boy, would I love to free a state to do it or a region, or a population of people who signed up within a region. You know, maybe everybody who signs up in Iowa or Nebraska or something. Let's see how it works. Let's learn.

I have some skepticism about the way we now put together catastrophic coverage which doesn't include long-term care. I think we are hiding lots of the costs in the burdens we're imposing upon women without taking account of the economic value of their service. And the catastrophic coverage as we've mostly talked about has only been doctor stuff. So, if we get seriously into long-term care, then we're going to have to figure out how to deal with personal wealth. And I'd love to see some substantial groups of people trying to figure out that.

So, I couldn't write exactly what I'd like to see put in place, but I'd like to see a dozen very smart people or groups trying it out in populations willing to try to be the pioneers.

And in the same way in answer to a couple of your comments, you know how would I deal with the ownership society and write a compelling narrative about caregivers. I mean, I think that we have to be very careful what metaphors we put forward and maybe to just deliberately try to put forward a multitude of metaphors that we could try on. You know, what got Medicare passed and what got us into the idea of their being social insurance was a sense that we were all in it together and that we were not going to let the weaker, the poorer or the people with fewer opportunities, whatever, among us fall farther than this, you know whatever the "this" was. That we were going to guarantee at least this level of income or at least this level of opportunity.

So that's a different idea than the ownership society. I mean, we commonly hold conflicting ideas in our minds. One of my colleagues used to say the reason the good Lord gave us big minds is so that we could hold conflicting ideas far enough apart that we could still function.

So, yes, we do want to be an ownership society and have an investment in our community and some control over our assets. And we also want — it isn’t just my mother that I want taken care of; I want your mother taken care of. I want anybody's mother taken care of. And we also feel ourselves to be part of communities and communities that to our credit have extended beyond narrow bonds of relationships or ethnicity or religion, we have in general been a reasonably generous society in wanting there not to be grinding poverty in our communities and being troubled by the persisting pockets of grinding poverty and lack of opportunity. When it's also up against the end-of-life, I think it even tugs at us more because now the person really couldn't just be a virtuous person and go out and get a job, but now they really are up against mortality which is one of those grand leveling forces, you know. No matter how rich or poor you've been, you go to your grave without assets. So there's a certain opportunity it seems to maybe find some metaphors.

I mean, I've been a family caregiver myself. I've certainly taken care of lots and lots of family caregivers. I think there are compelling narratives. But they engage in the community in some ways that we have not been familiar with engaging them.

I was the first hospice doctor here in Washington. We used to sometimes put signs on the elevators saying there’s someone in your building who doesn’t have any friends in the building and has lived here 30 years, a common occurrence, who wants to try to stay at home to as close to the end-of-life as she could do. If there were 8 or 10 people who would volunteer to help, she could stay here a lot longer. And, boy, there was never a time we didn't get 8 or 10 people.

There are sources of community spirit that we have just not even started tapping into. But we have to work with this. We have to figure out how we're going to make this work for us and what the balance is between those and our sentiments that we own what we own and we should have authority to control it.

But, again, this is the kind of group that can bring those to bear and can find some pros that might move some people, might help us frame things in some better ways. There aren't very many such places. There aren't very many forums that can say risky things, that can call on us for our deeper moral commitments and our long-term interests in a way that this kind of group can.
So, I guess the reason I’m delighted to have been asked to come here is to call on you to take that chance and to help us find the stories, the language, the constructs, the way of thinking that might help us meet these challenges in ways that a 100 or 200 years from now our descendants can look back on that and say boy, weren’t they a special group of people. You know, they really found the things that were of value. And we’ve lived those out rather than saying they let things happen just willy-nilly, they got caught in the sweep of events, never really stood back from it, never really figured out where our commitments lie and, therefore, terrible things happened.

You can’t stand against the tide, but a whole lot of people standing against the tide can turn it a little. So that’s what I hope you’ll do.

Thanks for having me here.

CHAIRMAN KASS: Thank you very much. Joanne, like most prophets, throws down a large challenge to the rest of us. Dan Foster, Dan and myself, all of us, face the difficult task of how to translate that into a kind of language that might get a fair hearing for the things that we all care about.

Joanne I think exhorts us not to sell ourselves short. Dan Foster reminds us that if we try to do everything at once, we will be ignored. And I think it remains our task to figure out, to negotiate between the best and the possible, holding out a vision and doing what we can.

So thank you very much for this very pointed challenge to the Council. We will do our best.

We're adjourned until — lunch is a little short, but we have a guest at 2:00. Let me urge you to be prompt.

(Whereupon, at 12:43 p.m. the meeting was adjourned to reconvene this same day.)

SESSION 3: AGING AND CARE-GIVING: ASSESSING OUTCOMES IN MEDICAL CARE

CHAIRMAN KASS: Would Council members please take their seats so that we can get started? Could I ask people in the back to join the table?

Our third session today entitled "Aging and Care-Giving: Assessing Outcomes in Medical Care" introduces us to an aspect of the subject that we haven’t considered before. We’re going to step back and look at certain features of the current health care system, its utilization, its priorities, and its goals.

Joanne Lynn’s presentation in the morning already raised for us the question not only about how much we are spending but what we are getting for it and what we are spending it on.

The Council has been exhorted to look at the question of overall issues of health care. When these things are generally discussed, both publicly and in the bioethics literature, they focus mostly on questions of justice and economy, equal access, insurance, wastage of resources at the end of life better used elsewhere in medicine or elsewhere altogether, but little attention is being paid, really, to the soundness of some of the underlying assumptions: First, that more resources for more of the same kind of care, more available for more people, will produce better health outcomes; and, second, that our overall medical goals are clear enough and reasonable and that our priorities in medical expenditure are sound.

The two sessions this afternoon are designed to help us examine these assumptions. They bear on the issues of aging and caregiving, perhaps only indirectly, and the implications for that topic will be left for us to draw.

But since attention to the health care and human care needs of the elderly are clearly affected by the functioning of the health care system in general, consideration of these practices based on these and other assumptions are surely relevant to our overall project in the area of aging and care.

In this first session, we are very fortunate to have with us Dr. Jack Wennberg, who is Professor of Community and Family Medicine, Professor of Medicine and Director of the Center for the Evaluative Clinical Sciences at Dartmouth Medical School.

He has been one of the leaders in the development of the field of evidence-based medicine and outcome studies, looking at various ways in which practices vary region by region and trying to raise questions about whether or not current care is, in fact, effective care.
He is also the principal investigator and series editor of the *Dartmouth Atlas of Health Care*, which examines these patterns of medical resource intensity and utilization in the United States. This project has done some reporting on the patterns of end-of-life care, inequities in the Medicare reimbursement system, and the underuse of preventive care.

We are very fortunate to have Dr. Wennberg here. We look forward to your presentation. Welcome.

**DR. WENNBERG:** Thank you very much.

I think what I would like to do today is break the talk into two parts with a period of questions in between. I think, Leon, you are going to do the moderating of that. The reason is because the topics are different and they are also complex. And I don't want to have to wait until the end to get some of the concerns and interest out on the table.

I trust that you have all had a chance to look at the manuscript that I sent down. So I'll try to be brief in terms of my presentation and concentrate initially on what I call effective care and preference-sensitive care. I'll come to define that a little bit further down here.

Just to give you a little background, the basic perspective that I bring to this debate about health care is that of an epidemiologist. And that was my training, and that is what I have been doing most of my life.

Instead of looking at the incidence of illness and trying to associate environmental factors with the incidence of illness, my particular interest was in associating or studying the health care system itself as a topic of investigation.

This goes way back, but I am going to bring you up to the last decade or so of this research. Beginning in the early '90s, we obtained access to the Medicare claims data, the full files for the whole program, at least for the traditional Medicare.

Using those files, we were able to divide the country up into regions based on the simple distribution of where people went for care, for hospital care, as a function of the zip code they lived in and the hospital they used. And this enabled us to divide the country up into some 306 referral regions. The variation between these regions will be the target of my initial comments at least.

More recently, we have also been able to look at individual hospitals. And since that is where the money is, I do want to share some of those results with you because I think if we really get into the problems here, you will see this as a multifaceted problem dealing with — depending on the category that we're talking about, the remedies are different. And the opportunities for reform are different.

But fundamentally the underlying problem in all of this work, with the exception of the effective care category, is scientific uncertainty and lack of clarity about the relationship between resource inputs, medical theories, and outcomes. So we'll come back to that.

Okay. Well, I want to talk about what I call unwarranted variation. And that is variation that is not explained by illness, patient preferences, or evidence-based medicine.

Most of us, I think, assume that most of medicine is warranted in the sense that it does correspond to these definitions and explanations, but, in fact, it doesn't. Almost all the things we see in the Medicare population demonstrate this extraordinary variation.

Effective care is the first category. This basically is a fairly restricted amount of care. Even though there has been an awful lot of emphasis on evidence-based medicine, so far we haven't found very many things that you can actually measure that are evidence-based.

Now, that's partly because the claims data don't allow us to, but also even when you go way behind the clinical trial definition of effectiveness, as Beth McGlynn has at RAND Corporation, you quickly run out of things to look for, even when you can do chart review.

So everybody seems to find underuse of effective care, no matter where it is. And this was the emphasis of an awful lot of the initial IOM work. And certainly when you hear about pay-for-performance programs now, they're going to pay doctors to do things they ought to be doing. It turns out that that is not a bad idea, that they should do what they should do, but whether you should pay them for it is another question. You already pay them quite a bit.

The interesting fact is that — and I'll give you sort of a — just so you can carry this thread through the conversation here, when you look at what correlates with spending in Medicare and what correlates with large amounts of resource use, it's not effective care measures. In fact, the effective
Care measures are better in regions that have less intensive care, which is fascinating. Fewer physicians lead to better effective care, maybe because there aren’t so many people involved in the care of the patient.

And when it comes to costs, there is basically very little correlation between the specific items of effective care and the costs in the region or in the patient cohorts experience.

Just to make it clear — and I want to spend just a minute with these dots here in case you haven’t thought about them before. There’s a dot up there for every one of the 306 regions. People ask me, why do I bother to put these dots up like that in that funny distribution. It’s because it’s easy to put a label on them so I can explain to you which dot is which. That’s the major reason.

This slide tells you quite clearly that when it comes to a simple thing about a diabetic getting an eye exam, where the criteria should be close to 100 percent of people, we’re not doing it enough in most regions. And, in fact, in some regions less than 50 percent of the population in Medicare are actually getting that eye exam, just taken a couple of years ago.

I’m not going to talk any more about this other than to say that in sort of a schematic way, we can say that in terms of the benefit-utilization curve, we’re under-using effective care. And that’s what this is meant to depict here.

So the U.S. is basically in the zone where more care should be done, but it isn’t. And the irony is this is cheap to do, but it just doesn’t get done. So that is kind of the bottom line on that category, I think.

Now, preference-sensitive care is of a different nature. It basically involves treatments for which there are options or conditions for which there are treatment options. A classic example would be a woman with early stage breast cancer who is faced with either a lumpectomy or a mastectomy decision.

In this particular case, the clinical evidence is pretty strong. And we do know that the mortality implications or the survival implications are about the same, but everything else is different. The lumpectomy involves radiation, possibly chemotherapy, and the possibility of local recurrence, which then would require further surgery. The mastectomy avoids most of those problems but clearly involves problems of reconstructive surgery and so forth.

I don’t think that anybody here would try to make the case that it’s the surgeon’s job to prescribe for the patient what he thinks she should have, but, in fact, that is the dominant pattern of practice for most surgical decisions of this type and is the source of an awful lot of the variation that we see, namely medical opinion that has not been modified by an engaging conversation with the patient about that patient’s own preferences.

So I’ve given you in a nutshell what my interpretation is of the causal factors and the practice variation that are most significant here. And I will try to amplify on this a little bit as we go along here.

This diagram here simply shows you how much variation there is among the 306 regions when you compare, on the left, hip fracture, for which the market actually clears of, quote, “need,” because everybody with hip fracture gets hospitalized in this country. And so the incidence of hip fracture is actually the major determinant of the distribution of care.

You can’t see it because the dots are too small, but there is one little place that is a real outlier on the low side. That turns out to be Hawaii. Hawaii has a very low rate of hip fractures. The rest of the country is very homogeneous in that.

Knee replacements, hip replacements, and back surgery are increasingly more variable. This reflects basically some of the underlying dynamics of the market for orthopedic surgery across the country.

Here is a snapshot of what is going on in four communities in south Florida. Fort Myers on the left does excess amounts of knee replacement, about 48 percent more knee replacement than the U.S. average, 45 percent more hip replacements, and 67 percent more back surgery. On the other hand, Miami is low in all of them.

And if you look at Fort Lauderdale, Fort Lauderdale is below the national average for knees, above it for hips, and at it for back. This is exactly the kind of pattern that you see: idiosyncratic patterns of surgical practice delineated by sharp boundaries as you move from one community to the other.
Fort Myers is contiguous to Miami. You have to go through a bit of the Everglades to get there, but it’s pretty close. And Fort Lauderdale is right next to it. So these patterns of practice are very idiosyncratic to the community, and that occurs around the country.

I was chatting with Leon before the talk here. The economic implications are considerable because over a decade of time, Fort Myers generates about $125 million more revenue from these 3 procedures just for hospitalization than would be the case if they were practicing at the pattern of Miami, so big money is involved in this.

The interesting thing — and this is part of the general phenomenon — is that you might expect that the relationship between knee replacement and the supply of orthopedic surgeons would be positive because, after all, orthopedic surgeons do these kinds of things.

Well, it turns out that the correlation between supply of surgeons and the rates of specific procedures which they do is quite low consistently for all of the discretionary surgical procedures.

And the reason in my opinion that this is occurring — and I think there is more than just my opinion behind this — is that orthopedic surgeons, for example, have choices. They could be doing sports medicine. They could be doing carpal tunnel syndrome. They could be doing other things. They could be doing knees and hips. And there is a comfort level that surgeons get with specific procedures, and they look for opportunities to do it.

Just to give you a specific study here, in the case of knee replacements, the Canadians became actually quite interested in what these rates were all about. And so they actually did a morbidity survey in which they did a questionnaire to find all people with arthritis that was sufficiently severe to engage the patient about whether they should have surgery. They did X-rays. And they basically found that the number of people eligible for surgery exceeded by a factor of ten the actual rates that they were performing.

Now, the interesting thing is that after that determination of need— that was, clinical need — they actually interviewed the patients and asked their preferences. Only 14 percent of that group actually wanted surgery. So you see that the excess morbidity that is available countered against the actual question about preferences is where these kinds of — it’s in that space that these kinds of problems are happening.

This is just to show you quickly that for all the procedures we look at, there is virtually no relationship between supply of surgeons — we’re talking about knee replacements, hip replacements, back surgery, CABG, PCIs, prostate surgery for cancer, for BPH, gallbladders, carotid arthrectomies, and, finally, external lower leg bypass surgery. That makes up basically 45 percent of the Medicare outlays for surgery.

None of these is related, but what they are related to is the rates over time. And this shows you for the 306 regions along the horizontal axis the numbers of knee replacements that were performed in 1992 and '93 along the vertical axis, the number that were performed in the year 2000 and 2001.

Now, mind you, the line of equality says there’s more surgery done everywhere, but there is very little regression to the mean. In other words, whatever is going on in the community ten years ago predicts the risk of surgery today. And that is a five-fold variation in risk.

So these are essentially embedded attributes of the local core of physicians. In these regions, we’re not talking about a lot of people doing these things. We’re talking five or six, sometimes seven or eight in these size communities, people who are actually doing these procedures.

So we find again for all these procedures consistently that what happened ten years ago predicts what’s happening today, very stable patterns of practice.

Now, what do we know about the causal issues from the clinical trial level? We know that if decision aids that are designed to help patients understand what is at stake in these operations and which clearly delineate the problems of values and preferences, that the use of these decision aids consistently leads to different outcomes than to control groups, which are getting usual practice. That represents essentially a clinical test of the theory that doctor opinion is different than patient opinion and that patients decide differently when they’re informed than they do when they delegate decision-making to the doctors.

A second very interesting aspect of that is that in almost all the clinical trials of decision aids — and there have been about 15 of them now — the rate in the control group is higher than in the intervention group. In other words, there’s a net drop in the surgical incidence associated with the
introduction of information to patients.

That is exactly what we saw in one study we did in Group Health in Seattle and the Kaiser HMO in Denver. We basically were able to measure the rates of surgery in these regions before and after the introduction of what we call shared decision-making or the decision aids, in a structured way.

The rates dropped 40 percent. And when we benchmark these rates against the United States distribution, which is the purple on this particular slide, we saw that the rate of the benchmark under shared decision-making was at the very bottom of the distribution of surgery rates in the United States at that time.

The clear implication is that the amount of surgery informed patients want may be much less than the amount now provided in the country as a whole.

So that brings us up to the final question then: How do we normatively understand and assess the implications of these variations? And at the aggregate level, what we can say is because of the way the decision process is now structured based on the old model of delegating decision-making to physicians, we simply don't know what the right rate of surgery is because we don't have models of where patient in-true-demand or patient-informed decision-making has actually led to an empirical result except for that one Kaiser example.

We do know that, on average, in all of the clinical trials, patients who are actively involved in the decision-making with informed patient choice choose less than the control group. So very likely in my opinion, we are on the downward side of this curve. We're providing more care than our population would demand if they were informed, but I can't say that with any certainty.

Now, that's a quick run-through, Leon, of the story on the preference-sensitive. And I think if you'd like to open it up for —

CHAIRMAN KASS: Why don't we pause and have discussion of this before Jack goes on with the other things?

I have a question. The benchmark here seems to be what the patients would choose if the patients had full information, full data presented to them. But if some skeptic were to say, "Patients talked to at some greater length will become leery of certain kinds of procedures and will opt out of having them, getting what they chose but going against their best interests," what would one say?

I mean, the true measure should be benefit to patients, which is not necessarily matched by giving them what they wanted. What you want to give them is what would be effective for improving their health.

DR. WENNBERG: Right.

CHAIRMAN KASS: Are there data on this with the follow-ups?

DR. WENNBERG: Yes, there is. Let me make one point clear that there are clinical criteria of eligibility. So this is not somebody who just happens to have Munchausen's or something and wants to come in and get involved.

So these are people who based on — well, let me give a specific example. In the case of prostate, the choice of surgery versus watchful waiting for a benign prosthetic hyperplasia— that's an enlarged prostate, noncancerous — it turned out that what really was at stake was a trade-off between sexual function and urinary tract function.

The urinary tract function was better managed with surgery than drugs or at the time we did this study initially, there weren't very many drugs at all; whereas, the patients who had surgery almost to a person would have retrograde ejaculation, a problem which incidentally the surgeons thought was a normal outcome, was not a normal outcome at all for a number of men. And when they were informed about that plus the probability, the relatively small probability, of incontinence and impotence, that became the big divide in terms of the decision process.

So it is, in fact, a more — if I had time to go into this, this is a very interesting set of questions about what are these trade-offs, how do we measure them, and how do we know that the decisions that aren't being made under this model of decision-making are better decisions than those that are made under the old model?

Our group has worked very hard at that, developing what we call decision quality measures. In this particular case, it was to learn through external questions about how much their symptoms bothered
them, how severe they were by a scale, and their concern about sexual function and then to use those measures essentially to predict choice.

It turned out that they did very well. So people who were quite concerned about their symptoms and were not concerned about sexual function were five times more likely to choose surgery than those who were the reverse. So that these were very — validation I think is at the level.

The other thing that these decision quality measures allow us to do is to quantify whether people in the control arm knew what they were doing. And it turned out they didn’t. In other words, they did not have the natural history right, and they were not making decisions that were reflective of this underlying preference.

It is this sense of subjective trade-off that we're talking about here, which is very different than the classic clinical model, that there is an objective need and it has to be treated as binary. Either you've got it or you don’t.

The interesting thing is that only 20 percent of the patients who were severely symptomatic from urinary tract function under this model actually chose surgery. It was quite similar to the result that we saw in the Canadian study, which I mentioned a few minutes ago, where only 14 percent of patients who were clinically qualified did it.

One of the other interesting clinical trials here was in Canada, where you hear a lot of argument that they are under-served in Canada for bypass surgery. Well, it turned out that a study conducted on the waiting list for people with stable angina, not the severe blockage but the stable angina part, we saw a 22 percent reduction on the waiting list of people who were already lined up by their doctors for surgery.

So this preference issue is extremely important in terms of sorting out the variation in practices that we see.

CHAIRMAN KASS: Thank you.

Paul McHugh?

DR. MCHUGH: Thank you.

I think you have answered my question because I was just asking about the TURP (Transurethral Prostatectomy) for BPH (Benign Prostatic Hyperplasia) and how its association was down between 1992 and 2000. Of course, that was the time when Flomax and Proscar and all of those drugs began to appear.

DR. WENNBERG: Right.

DR. MCHUGH: That could explain some of this—

DR. WENNBERG: I think it definitely does.

DR. MCHUGH: — the fact that there were these alternatives with BPH. After all, sometimes you get to the point where, the patient gets to the point where whether he wants it or not, he's got to have it. And those drugs have at least avoided that kind of problem for patients. And isn't that —

DR. WENNBERG: I think that's the right interpretation of that. Thanks.

CHAIRMAN KASS: Ben Carson?

DR. CARSON: Thank you for that.

In terms of decision-making when more information is given and people are opting out of surgery, doesn't a lot of that depend on who is providing that information? And also do you think it's important to distinguish the various types of surgery?

For instance, people with trigeminal neuralgia, an extremely painful condition of the face, very frequently do not get into the hands of a neurosurgeon. And they suffer for years, sometimes for decades, when we have very simple ways of taking care of that problem. And seizure surgery, of course, is the other big area.

DR. WENNBERG: Clearly, the problem, from a systems perspective is to make sure that the patients who are in the primary care or other specialty care are not kept from referral on the basis of
the doctor’s opinion, as opposed to the patient’s opinion, about what should be done.

So in the case that we are examining here of BPH, we’re not sure that we didn’t miss people who would have wanted it because their primary physicians never referred them. So it’s a two-way street. And it basically says that if you’re going to change the practice, you have to change it systematically for the referral process but also for the process of people who come directly to the specialist. So it’s an issue.

It sure matters who gives the data, I mean, the information. That’s the problem. It’s not that these patients don’t get information. Everybody gets informed consent. But the problem is it’s possible — and I did not go into this, but these decision aids are the result of, in the case of prostate work, a decade-long research project into what’s at stake.

And that was part of the Agency for Health Care Policy and Research’s original mandate, to basically study these decisions and to create rationality that made sense to patients from that work.

And the decision aids are carefully examined for bias. Bias is something that is everywhere. But the objectivity of the decision aids is basically a vetted process that goes through both patient-focused groups, objective questionnaires, and physician groups.

I can tell you one thing is that while patients tend to believe it’s biased from the direction for which they have made the decision, the physicians believe it’s biased in favor of the other specialty. That’s just a truism in this. You figure it. The nice thing is that you do this long enough, and everybody finally gets tired of the process and says, “Okay. It’s okay.” So the long-term goal in my mind here is to improve upon the decision aids by iterative research, which learns better how to actually understand preferences of patients, their stability, and how to measure the fact that the decision that they ultimately made was coincident with their preferences.

**DR. FOSTER:** Let me ask you this question. I mean, I think it’s very interesting to do all of these comparisons, but do you think that there are adequate controls?

Let’s say that an informed patient decides against prostate surgery, as opposed to implanting seeds or whatever. What is the evidence that the patient decision was the right decision?

I mean, they may say, "Well, I don’t want this," but, in fact, most physicians will talk to other physicians.

**DR. WENNBERG:** Right, right.

**DR. FOSTER:** I mean, I can tell you very clearly if I have an illness, which I don’t, I will go to a physician. And I don’t make the decision myself, no matter what he tells me. I end up saying, "What do you think is the best thing for me?"

So my question is, the mere fact that a group of patients — I know you have thought about this as much as I have — say, "Well, we’re going to opt not to do this," —

**DR. WENNBERG:** Right.

**DR. FOSTER:** — do we have strong evidence that their decision in terms of outcome was the proper one? I mean, we talked about prostate. John McConnell published a paper that got him into the Institute of Medicine about predicting when you were going to need intervention and so forth and so on.

I mean, we have those data, but my question is, do you have strong evidence that the fact that the patient decided this way after information and knowing about the complications was the right decision in terms of outcome for the future?

**DR. WENNBERG:** Well, in the case that you raised, namely prostate cancer treatment, nobody has any good evidence on it. So we wouldn’t have any either.

It’s important because you had said you’re the patient. You’re going to go to the urologist, and he’s going to decide what you get while if you went to the radiotherapist, you can guess what you would have gotten. So simply by choosing the specialty, you have fated yourself for a decision.

I would beg to argue that the model that you have just put on the table is the old model. That is how patients have behaved. What I am trying to say now is that patients when they are in a care system that bothers to let them understand their options and uses validated decision aids, you get a very different decision.
Let me give you another example that might help here. We have used the decision aids in clinical trials, of surgery, for back surgery versus watchful waiting, in which the objective of the video is to explain the treatment options but to also explain the scientific uncertainty, which is not usually explained.

You wouldn't go to a urologist probably and tell you, "Well, the clinical trials for this condition have never been completed, but I think this is what is going to happen." You get a very different story than if you asked him "What should I do?" and he'll say, "Of course, you should have that procedure."

So it's, in fact, this cultural shift that is almost exhibited, quite interestingly, between our points of view on this is what we're about right now, learning how to communicate uncertainty, communicate values, and so forth.

And it does mean that patients have to begin to understand that. Medicine is not written in stone. We don't know the answers very often, as opposed to the lumpectomy situation, where the clinical trials have actually clarified that these two procedures have equivalent outcomes.

And I can tell you that you wouldn't want the gynecologist deciding whether your wife should have a mastectomy or a lumpectomy based on the fact that he always recommends mastectomies, which some of them do.

Do you follow me?

**DR. FOSTER:** I think I do follow you. Yes, I do.

**DR. WENNBERG:** It's an exciting kind of concept, but it's not intuitive. The one thing I can be quite clear about is that the evidence from the use of decision aids is that: (a) patients made better decisions according to preferences; and (b) satisfaction is fine. So people don't mind getting involved in uncertainty.

**DR. FOSTER:** But I don't think you've answered my question. I presume that most good physicians will change with the evidence. You know, we gave estrogens for a long time, and now we don't do that or we understand that probably nobody should have back then. You know, the evidence comes in. I presume that that would be the case.

But the question I'm asking — and maybe you've answered this and I didn't get it — it's one thing to say that if you have a system — you call it the old system. I mean, sometimes old systems are better than new systems, as you know. I mean, many times they are.

But what I want to know is it's not whether they got a mastectomy or a lumpectomy. You can get the outcome then. I want to know about the change of decision.

Look, I'm an endocrinologist. Let's say that if a person comes in and has got hyperthyroidism, one thing I can say is, "Okay. You can treat it with radioactive iodine. You're going to get this. You get surgery. You're going to do this. You know, if you want to take long-term propylthiouracil. All of those things will make you well. And there are risks and so forth with each one of them." And so let's say that the patient then makes a decision that on the basis of the facts that they learn that they are going to choose to do surgery.

My question is, do we have firm evidence that that decision conforms to outcome in a higher percentage than if you use the old system? I guess that's what I'm saying.

My guess is that if you got sick and you had something that was not a streptococcal sore throat or something like that, that you would probably ask around at Dartmouth and so forth. And what you would say is, "Who is the best person to treat me for this?"

And that person may tell you, and you may decide to do one. He may give you options. But don't you —

**DR. WENNBERG:** Let me try —

**DR. FOSTER:** The question is, I guess I'm saying, is, do we have data that shows that the patient decision when informed has a better outcome than the decision that was made by a physician, what you're calling physician preference here? I'm trying to separate out the economic reasons for doing a lot of surgery or something.
DR. WENNBERG: Let me say that we have to keep the categories straight. So, in other words, if there is something that works and everybody knows it works, we're not talking about a preference-sensitive problem. What we're talking about is, the major categories that this applies to is discretionary surgery, where you could do this or you could do that.

Sometimes the outcomes are fairly well-known. And sometimes they aren't. The ultimate goal that we have is actually in cases, like back surgery where there were no clinical trials, to actually conduct them.

And we conducted the clinical trial by using the decision aid. And we argued forcefully I think with our colleagues that in this case, the ethical criteria for entering the trial should be patient equipoise and not doctor equipoise because we couldn't find very many surgeons who were at equipoise about the value of back surgery.

So what this allowed us to do in 11 center sites was to actually get over 900 people enrolled in the clinical trial. And we're also following up those who had strong preferences. So we're able to look at the internal and external validity problem.

So when the probabilities are not known but the treatment is optional, then the long-term ethical, in my opinion the ethically correct way, is to learn by works, not just to keep doing things when we don't know the answer.

So there's this distinction between understanding what the outcomes are given the choice of treatment — sometimes we know, sometimes we don't — and then the question about the value to the patient of choosing one way or the other.

Go back to the prostate situation. We have actually done this a number of times. We have informed men about the clinical uncertainties associated with the treatment. And some of them will say, "I want that surgery because I think the evidence, shaky as it is, is better than nothing."

Others will say, "That evidence is shaky, and I don't want to risk the incontinence and impotence," which we do know a lot about. And you find people divide on that. They really do.

So if I can try to make sure that my point isn't getting lost here, the question of preferences has to do with the choices between the options given the knowledge we have. The question of outcomes has to do with how good are the studies that have established our information base, of which we're informing patients.

In many cases here, it's shaky. Prostate cancer is a great example. And we do need to do these studies.

CHAIRMAN KASS: There are a couple of people in the queue, but just if I could intervene here and see if I can clarify for myself. In a way, Dan reasked the question I asked also.

I take it that the point of departure is this very wide variation, say, between Miami and Fort Myers, a much wider variation for knee replacement, hip replacement, and back surgery, which are relatively optional compared to hip pinning for a fracture, where the variation is much smaller.

I suppose, I mean, one possibility is to say the people in Miami are not having their backs done sufficiently. They're being under-served and that it might be a mistake to talk people in Fort Myers out of doing that by giving them more information so they choose like Miamians.

But I think the presumption is that somewhere that there is this tremendous variation means that there might very likely be a certain amount of excess surgery. I think that's some of the starting assumption.

And then the question is — and you don't even have to attribute bad motives. It might be certain sort of standard ways of proceeding in various hospitals or in various regions, where people do it the way they were trained.

Then the question is, what happens if you lay out all of the details where the cost-benefit calculus of the patient is somewhat up in the air? I take it the point is in those cases, the argument is that the patients are probably as well able to make that kind of calculated decision where, really, you're dealing with optional surgery, rather than with, say, life-saving surgery. Is that —

DR. WENNBERG: Yes. I mean, this would not apply to hip fracture.

CHAIRMAN KASS: So I take it it was a kind of limited scenario where Jack was suggesting that
this kind of information — where what you're getting is a kind of trade-off of certain kinds of benefits at certain kinds of symptoms, where that reduces the incidence of surgery, where you suspect that there is a certain kind of excess, might not be a cause of concern.

Now, I don't know that that is reassuring or whether that is a correct understanding of the problem.

**DR. WENNBERG:** I think ultimately the ethical question to me has been it's not a good idea to do surgery on people who don't want it. And we have never been very good at finding out what people want.

That’s the story here. I don’t want to give a lumpectomy to a woman who wants a mastectomy just because I have been trained that lumpectomies are the wave of the future. And that’s because there is heterogeneity among people. We all know that. We’re not all the same.

Medicine is fraught with decisions for which there are options for which information is not complete. So sharing uncertainty with patients is part of the ethical requirement for the discourse that we’re after. An obligation on top of that is to follow up with patients to find out what happened, preferably with randomization if you can do it, but if you can’t, just do it on the basis of the cohorts.

Just an example on this very study we’re talking about here is that one of the big uncertainties about prostate surgery when we were engaged in this research was, what is the incidence of acute retention if you don’t have surgery.

The urologists were all over the place in terms of what they thought it was. Some thought it was about one percent. Some thought it was ten percent in a year. Well, by having a whole bunch of people who had significant prostate disease that we were following, we answered that question within about two years very well. And it was quite low, actually.

So if it had been ten percent, then the whole decision process would have been very different because you would have to face that gradient.

**CHAIRMAN KASS:** Let’s have a couple of questions. Ben Carson and Gil, and then we will let you do the second part.

**DR. CARSON:** Just sticking with the whole prostate situation, you know, in the 1980s, Pat Walsh worked out a wonderful nerve-sparing prostatectomy procedure. And a number of other people have adopted that. And there by the mid ’90s were a handful of people who had spectacular results with prostatectomy. And that number has increased exponentially since that time.

Is that kind of information utilized in this new information system? A lot of people think that a surgeon is a surgeon like a plumber is a plumber, and it’s not true.

**DR. WENNBERG:** Yes. There are two questions in a sense that we are being asked there. I think one was whether or not the specific surgeon that was about to do the procedure was giving his statistics or her statistics, rather than Pat Walsh’s. That’s a big problem.

There’s also a question about what Pat Walsh’s statistics really are, too, because systematic follow-up of — not Pat. He likes to do this, but he also categorically does not operate on anybody over 60, 65 if you really push him. And that’s not what is happening in most practices. So the question about how to get surgeon-specific information into these kinds of databases is complicated and difficult.

The other question is about whether there has been innovation. The obligation of doing decision aids is frequent updates because new information comes in all the time. Sometimes it’s positive. Sometimes it’s not. Actually, when Vioxx went off the market, it upset one of the decision aids on osteoarthritis. And it had to be dealt with immediately.

So I don’t know if that answers your question, but it is a complicated one, particularly when one gets into the question about operative mortality variations, too, and how they become communicated to patients. The statistics are difficult because of the incidents, even among a not-so-good surgeon, and still pretty low, thank God.

**CHAIRMAN KASS:** Gil Meilaender?

**PROF. MEILAENDER:** Ben, a plumber is not a plumber. There are distinct differences. *(Laughter.)* Is there a way to sort of factor into the thinking that you’re doing about this or is it even important to factor in the possibility that it’s not just what you a while back, I think answering Dan, talked about as a culture shift but there might be temperamental differences?
In other words, maybe I really want all of the information. And maybe the person next to me experiences a greater level of contentment with their care if they just say, “What would you do, Doctor?” and the doctor says something.

CHAIRMAN KASS: Right.

PROF. MEILAENDER: How is that difference, which isn’t strictly — I don’t think that’s simply changing culturally. There still are and always will be people who react differently. How does that make a difference in how you think about these things?

DR. WENNBERG: That’s a very good question. Quantitatively, we find in most of these clinical trials about ten percent of people fit that category after they have looked. They still don’t know what they want.

And in this case, we have taken a fairly simple rule of thumb that if the patient doesn’t know what he wants, do the less invasive thing because some day he might find out what he wants and he will come back to you.

So that it’s basically very pragmatic. If the patient doesn’t have a choice for surgery, I wouldn’t do it. So it does have a simple pragmatic answer.

CHAIRMAN KASS: Why don’t we go ahead, Jack, into the second part?

DR. WENNBERG: Sure. Well, having gotten you through all of that difficulty, wait until you see the next part here. This is basically now dealing with supply-sensitive care. And the distinction between preference-sensitive care and supply-sensitive care is partly because of the role of supply itself, as I will show you, but also because in preference-sensitive care, the treatment options are fully articulated in terms of medical theory and sometimes evidence. Surgeons don’t operate without a good reason for it, even though the reason may not be ultimately correct.

But in the case of supply-sensitive care, what we are talking about is essentially the frequency with which chronically ill people visit physicians, not surgeons but medical specialists and general internists and family practitioners, how often people with chronic illness are hospitalized, how frequently they’re put in intensive care units, and how often they’re monitored with diagnostic testing and imaging.

For the concept of how frequently should I revisit or schedule, our patient with moderate congestive heart failure, there are basically no clinical guidelines at all about this.

It’s never entered the discourse, clinical discourse. You don’t go to clinical meetings and see physicians arguing vehemently about every three months, every five months, every six months. In fact, it turns out that interval shifts from six months to three months accommodate a doubling of the supply of physicians because it takes that much more time to see those patients.

And so it is the question here of the variation in the intensity with which chronically ill people are treated. And the reason we are focusing on chronic illness is because that is where most of the visits, hospitalizations for medical hospitalizations go, not surgery but go for the Medicare population.

So what we see is huge variation in the number of primary physician visits, particularly medical specialist visits. They show about a five-fold difference between the regions, five-fold differences in congestive heart failure and COPD discharges. So that’s what we’re looking at here in terms of the basic problem.

When we correlate the hospitalizations for medical conditions, the green dots on the slide, we see a strong relationship between hospitalization and the number of acute care beds in a region. And that’s not surprising because acute care beds tend to be fully occupied, maybe not so much anymore. Maybe that’s why we only explain half of the variation, but that’s an awful lot of it; whereas, hip fractures, which we have already discussed, are essentially where the hospitalization rate is pretty much under-determined by the incidence rate. We don’t see any relationship between bed supply and admissions or hospitalization for hip fracture.

I might remind you that under the classic concept that utilization was regulated by scientific information and effectiveness criteria, the hip fracture would be what you would expect. But, in fact, hip fractures — there are only about three other conditions that we have looked at that even come close to the hip fracture. One of them is colectomy for people with cancer of the colon. Most people who have cancer of the colon will ultimately get a colectomy, even if it’s late.
And it used to be acute heart attacks would follow this pattern, but recently there have been so many redefinitions of what an AMI is in terms of the enzymatic definitions that you see increasing variation in the use of hospitals for AMI also, the same kind of thing we see for the physician visit rate.

So here is the number of cardiologists per capita ranging from 2.5 to 12.5 or about 5- or 6-fold difference. And that's the visit rate to cardiologists, not surprising because cardiologists in large part see people who are over 65. It's not as if we were pediatricians with this. So that is kind of to be expected.

Again, this is quite consistent with the scenario when you have more physicians you get more visits or, in fact, what is happening is that the revisit rates are being narrowed as you get more, there being a limit to the number of people with cardiological problems.

Now, the kind of obvious question here is not so much that it varies but, rather, what's the value of the additional increment in utilization? That's the question that underlies this question about whether we are rationing care in the low-rate regions, or are we overtreating or is there excess capacity in the high-bed side? So that's the kind of question that comes out of that.

We have been pursuing this problem now for a long time. And consistently we have found basically no relationship between health outcomes that we could measure at the population level and the utilization of hospitals and doctors. In other words, we see in Miami twice as many hospitalizations per capita for medical conditions as we see in Minneapolis or we see in Los Angeles.

The study that I am going to talk now briefly about essentially took the area dimension down to the cohort dimension, instead of asking the question about general survival in the region among Medicare patients. What about people who had had a heart attack, cancer of the colon treated surgically, and patients who had had hip fractures?

These were the kind of conditions which we could have some confidence were being treated similarly between regions. Particularly in the case of heart attacks, we were able to get some clinical evidence that allowed us to sort out these newer categories of AMIs that are enzymatically determined.

Then to follow these people over long periods of time, five years, and ask the question if they lived in regions that had high-intensity care, did they do better than the ones living in the low-intensity care regions? So it was an aggregate study across the country.

What I can show you on this slide is that comparing the highest quintile to the lowest quintile, we saw about 60 percent more Medicare spending, 32 percent more hospital beds, lots more medical specialists and surgeons and so forth, and correspondingly high utilization rates.

But what we didn't see was any improvement in outcomes. In fact, when we compared the relative risk of death over that five-year period, in each case, the mortality rates were higher in the more intensive regions. Heart attacks, colon cancer, and hip fractures all had significantly higher mortality rates in the high-rate regions than they did in the low-rate regions.

In addition, when we looked at other data sources that Medicare provides in terms of functional status satisfaction, we basically saw no difference, which is coming at least in the directions about quality of life.

Finally, fascinatingly enough, access was actually worse in the high-rate regions for such things as preventive care and beta blockers. The reason I think that may be happening is that in the high-rate regions, many more doctors are involved in the treatment of patients. And the continuity of care question is really very questionable there. I’ll come back later and talk about that.

By our understanding of the available data, we can say that at best, we’re at flat on the curve, which means we’re not getting anything out of this incremental investment or, as the mortality evidence suggests, we’re actually on the downward slope. So we’re losing, as opposed to gaining.

Now, you could ask me, how in the world could that ever happen? Well, if you pay attention to the medical error literature, where the claim is that about one percent of Medicare population experiences an iatrogenic death for each hospitalization that occurs; in other words, one out of 100 hospitalizations is associated with that, if you do twice as many hospitalizations, you’re going to have twice as many people on a per capita basis who are actually dying in a region from the iatrogenic illness or medical illness. And that, in effect, is quite consistent with what we’re seeing in the data.

The importance of this last category is — I can quickly illustrate here by the green, is the low-
When you increase spending, you don’t get more effective care. Ironically, you don’t get more preference-sensitive care. In other words, the likelihood of having bypass surgery in Minneapolis is just as high as it is of having it in the high-cost regions. But what you get is a lot more hospitalizations, medical specialist visits. And this percent, seeing ten or more doctors, is our measure of continuity or lack of continuity.

So that’s the story at the regional level as we look at it across the United States. The question is — I don’t know whether, Leon, you want to take questions now, but I do want to go over to look at what is actually happening in some of our academic medical centers.

CHAIRMAN KASS: Why don’t you finish up, and we’ll hold the questions to the end.

DR. WENNBERG: Okay. Because I’m going to be dealing with the same problem, namely the supply-sensitive care, rather than the preference-sensitive care.

In the last few years now, we have been working to change or to add the population-based analysis to the experiences of specific hospitals. And that’s possible because when people become chronically ill, they do not change providers very often. So if you follow back from death for two years and look at the providers that were used during that time and assign the patient to the hospital that they most frequently used, you end up with loyalty of 80 to 90 percent of the care being actually delivered at that place.

So we have been able through this process to quantify the amount of care provided in managing chronic illness across these hospitals. We have concentrated on end-of-life care. There were a couple of reasons. One reason is that I think people do not resist our argument that when you’re about to die, you’re pretty sick, no matter where you are.

So measuring variation in end-of-life care is a way of implicitly controlling for illness differences, particularly if one goes to the trouble of case mix adjustment because some cancer, for example, has lower utilization rates than congestive heart failure. But by adjusting for that, you can take care of that problem.

This is the difference that we see among what we call the 77 best U.S. hospitals. This was slightly tongue in cheek. This was done in that British Medical Journal article. We took the ones from the U.S. News and World Report list of the best hospitals in the United States for geriatric care and for chronic disease management basically just to see how different they actually were.

What you see here is the average number of days that patients will spend in hospitals ranges from around 9 days at the low end of the distribution among these hospitals up to almost 28 days in the high end of the distribution. Remember, that’s the average number of days people in these cohorts with chronic disease are spending in these institutions.

If you put labels on them, you can see some fairly familiar places. Patients who are loyal to NYU spend almost a month in the hospital, patients loyal to Stanford about ten days. UCSF is about 11.5 and UCLA 16.1. You actually do see these extraordinary differences within the University of California’s system. I just showed two of them here.

What you then go on to see is this interesting association here, namely that if you’re high for one disease, you’re high for all diseases. This (slide) happens to compare congestive heart failure patients to cancer patients. And if you’re high for cancer patients, you’re likely to be high for congestive heart failure patients.

The black line is equality. So cancer patients get less care on average than congestive heart failure patients. But what really matters about how much care you get is not the disease you’ve got but the place where you’re given care.

This is also true for black-white comparisons. Blacks get slightly more care in the last six months of life than non-blacks, but what really determines how much you get is where you’re going. And that turns out to be true for all the conditions we looked at and for all of the different measures of utilization that we used.

Here’s the number of physician visits in the last six months of life. NYU is using 76, and Stanford is using 22, almost 3 times as much — actually, more than 3 times as much. Cedars-Sinai in San Francisco is 66 visits on average per person, UCLA 43.9, and UCSF 27.2.
Days in the hospital are related to physician visits. If you are in the hospital, you are much easier to visit. You get lots of referrals. So lots of time in the hospital equals lots of physician visits.

Intensive care units, let me just go back to this. The same study that I showed you before at the regional level for all hospitals was repeated to show the same thing happens among academic medical centers, namely academic medical centers located in regions with greater intensity of care, actually do not have better outcomes. They have slightly worse outcomes than those in the low-rate regions. So it’s a consistent finding.

And this basically is a day spent in intensive care. Notice the differences between the University of California in San Francisco, where you have 2.6 days on average and UCLA, more than a week in intensive care on average for patients in the last 6 months of life.

Deaths in hospital associated with admissions to ICU, 20 percent of Mt. Sinai Hospital and 36 percent at Cedars-Sinai. These issues have a lot to say about the quality of dying, for sure. I’m not dwelling on that at this time, but these are real people. And 36 percent of people at Cedars who happen to use that system are going to end up on average dying in an intensive care unit, compared to 20 at Mt. Sinai. And there are other hospitals who are even lower. I just didn’t have them named here.

Now, the final kind of thing I want to talk about here is that this gets a little bit back to what some of the options might be for actually doing something about this. In addition to measuring utilization, which I have just gone through, we also are able to measure resource allocation. So how many doctors were used? What type of doctors were used in treating these populations? And also how much money was spent in treating them?

I just want to briefly show you that this is the number of primary care plus medical specialists whose labor was allocated. I won’t have time to go into the details of this, but these are standardized full-time equivalent input. So you can compare one place to the other in terms of the actual labor inputs. It’s based essentially on the RVUs that were allocated to the different places.

So NYU is using 24.6 physicians, whereas, Stanford is using 8.7 for treating essentially the same patients over time. UCSF falls where it falls. Cedars-Sinai Medical Center in Los Angeles is again quite high.

Here are the differences between medical specialists and primary care. The Cedars system and the UCLA system are highly dependent on specialist care. So if you divide specialist by primary care physicians, you get 2.8, a ratio of 2.8, at UCLA. If you do the same thing for UCSF, you get 0.67. In other words, UCSF is using more primary physicians than is UCLA by quite a bit.

Finally, costs. Payments along the vertical line shows you how much money Medicare spent on these patients in the last six months of life, ranging from around $11,000 upwards of $35,000.

Along the horizontal axis is how much money was spent for the same patients in the 18 to 24 months prior to death. Of course, it’s a lot less. It ranges from 2 and a half to 2 to around 7 and a half, still a 3-fold variation or a 2 and a half-fold variation, but notice that they are highly correlated.

So, in other words, what we’re seeing here is not just an end-of-life phenomenon but, rather, a consistent difference in the threshold for treating chronically ill people across time, which could have been looked at in terms of visits and any of the other parameters I have shown you.

I’ve chosen this one because of another point that I want to make. And that is, when you look within a community, like San Francisco or Los Angeles, there is a great deal of variation in total payments and utilization among the hospitals actually located in that region. Some of them are spending well below the average of the region and some are spending well above the average of the region.

And that introduces some very interesting new information and debate for the so-called pay-for-performance strategies that are unfolding around the United States right now because it means that payers who are interested in locating efficient hospitals with regard to chronic illness can actually locate them through this data set. And opportunities for selective contracting for otherwise rewarding patients or rewarding physicians who are more efficient could be devised.

I don’t have a prediction about what will happen, but we are going to release this information nationally sometime over the next few months, starting with California, where we have already made connections with both the academic medical centers, some of them with the quality improvement organizations and with a business group. We’re trying to work out ways that this information could begin to filter back to see if we can affect change in California.
So I think that kind of gets it. I just wanted to say we find widespread underuse of effective care, things that doctors believe work and do work because of clinical trials.

We call it misuse of preference-sensitive care because it should be based on informed patient choice, but generally it’s not. And then we say an overuse of supply-sensitive care, particularly in the management of chronic illness, based largely on the fact that we find no marginal value in the increased use of care.

In terms of the things that need to be done, we need to work on the underuse of effective care. And that’s actually happening fairly well around the country. People are willing to pay people to do more. But we need to learn what works.

These questions that were raised here about what the actual outcomes are here, we need to assure informed patient choice. We need to achieve efficient and effective management of supply-sensitive care, namely chronic illnesses.

Finally, — this is a tough one — we have to achieve efficient allocation of resources geared to the size of the population served. The measures that I have just discussed allow you to know where those hospitals are. The question about how to downsize the excessive investment in acute care in this country, of course, is another story.

CHAIRMAN KASS: Thank you very much.

The floor is open for discussion. Robby?

PROF. GEORGE: If no one else is jumping in, if I could take Dr. Wennberg back to the preference-sensitive care issue? I just wanted to clarify for my own sake something in the exchange between you and Dr. Foster.

Is it a kind of presupposition of the profession that there will always be a right answer to these care choice questions, although it’s often difficult to know what the right answer is? And then you have the question, well, since it’s difficult to know what the right answer is, should the doctor make the call or should the patient and the patient’s family make the call or is it the case that in some cases, what the patient and doctor are faced with is not a choice where there is a right answer but there is a choice where there is no right answer? There are incommensurable pros and cons here.

The case that Dr. Wennberg cited about the patient before the development of better-quality drugs facing the question in the case of benign prostate disease of a TURP outcome where there would be diminished sexual function, on the one hand, or an outcome in which there would be diminished or problematic urinary function, that sounded like to me — I may just be misunderstanding — that case sounded to me like an example of a case where there is not really a right or wrong answer. There are incommensurable advantages and disadvantages to the two.

So that since it is not a question of trying to get the answer right in a situation where it is difficult to know what the right answer is but, rather, just with a choice that doesn’t emit a right answer in a case like that, would there be any argument for the doctor making the decision, rather than the patient?

It would sound to me as though there would not be any argument for the doctor making the decision, that that is just a pure decision that is left for the patient as to which of those two kinds of outcomes he would prefer to live with, either Dr. Foster or Dr. Wennberg. I just would like to have that clarified.

DR. WENNBERG: What you just defined is what the preference-sensitive care category is all about, basically. Options for which — and I think I am going to challenge you on one thing.

There is a right answer, but it’s not in the doctor’s head. It’s in the patient’s head because the patient has to sort out his values with regard to sexual function and urinary tract function. You only can learn these by asking questions about that.

PROF. MEILAENDER: But that’s a values-determined —

DR. WENNBERG: Exactly.

PROF. MEILAENDER: — conception of right outcome, as opposed to —

DR. WENNBERG: A probability —
DR. WENNBERG: — because the probabilities in this case were pretty well understood. You got a lot better improvement in urinary function, but you also had a high probability of retrograde ejaculation and the other problems. So that was not a decision where there was a scientific uncertainty. It was a question about the values.

The value side in our formulation of informed patient choice, as opposed to informed consent, belong to the patient as an active participant in the decision process.

PROF. MEILAENDER: So we're really talking here about two separate cases, one where there is scientific uncertainty. And there would be at least some argument in that situation for just letting the patient make the call, although others would say let the doctor make the call, and then other cases where it's not a question of scientific uncertainty. It's sorting out the patients' preferences, strictly speaking, values or desires. Am I right?

DR. WENNBERG: Can I come back to you?

PROF. MEILAENDER: Yes, please. I'd like to —

DR. WENNBERG: Essentially what the surgery for cancer, not for BPH —

PROF. MEILAENDER: I understand, but the cancer, it would be a different case.

DR. WENNBERG: Well, basically the way we frame that question in terms of our understanding of what in the subjective mind of the patient is at stake is at follows. Here is a set of evidence about the range in which the clinical trials if they were done would show benefit.

The most you can get out of this is a 10 percent reduction or a 15 percent reduction, whatever it happens to be, improvement in life expectancy. Against that, you've got to basically have a very strong probability of incontinence and impotence, even despite Dr. Walsh. It's still a big problem around the country.

So the question here is essentially the patient has to make a bet between a wager that the clinical trials if they came out would show enough improvement so it was worth it to him. And some people would just say, "Okay. I'm going to do that because I want to. I don't want to risk this thing. And my dad died of prostate cancer." That, by the way, is a big deal. So they go that route.

And other people will say — and we see it all the time — "It's just not worth it for me given my current situation, my current age, and all of that kind of thing."

The thing I would most like to do is I would like to convert that opportunity into clinical trials so we actually can begin to resolve these problems.

Where there is such strong opinions on different sides, the urologists, the radiologists, and the general internists, particularly in the U.K., are completely against this thing. In this country, they have become a little bit more persuaded. But it's a real deal.

CHAIRMAN KASS: Peter?

DR. LAWLER: This is a scenario about which I know nothing, but this bothers me what you said. Let's say I'm old, which is far-fetched, and I have a chronic disease that will kill me, like congestive heart failure.

I would think I should move to a research university town, where I get superior medical care, but this turns out not to be the case. I would just be in the hospital prodded by specialists a lot, go through a certain kind of medical torture that wouldn't produce a better outcome.

And the reason for this, if I understand your paper correctly, is because in an area I am now living, there are lots of hospital beds and lots of specialists.

So I should move to a more rural area, where there aren't so many hospital beds, aren't so many specialists, where they wouldn't want me to be in the hospital much. I would just see the same old boring doctor all along, have the continuity of care, and die about the same time. Is that about right?

DR. WENNBERG: You might not have to move. Let's say you're in Los Angeles. The variation that we saw in these slides is not quite replicated, but it's definitely in the same trend within L.A.
So if you really did not want to get involved in this business, (a) the quality measure that shows that if you go to this place, you would at least get your diabetic eye exams because we can measure those at this level. It's good quality from that perspective.

It's all over the park with surgery, but you're not going to do that. You're going to worry about congestive heart failure. Then you as an informed patient would say, "Doctor, I want to go to that hospital, and I want to seek care there." So you don't have to move.

**DR. LAWLER:** You have kind of an iron law here that the beds will be filled, the doctors will be used. And so what is the remedy to this? Fewer beds? Fewer doctors?

**DR. WENNBERG:** Well, achieve an efficient allocation of resources is what I have said here.

**DR. LAWLER:** But be a little bit more specific perhaps.

**DR. WENNBERG:** Well, we definitely have in my opinion an excess capacity in the acute sector for managing chronic illness. That includes the whole group.

Now, if you want to get into the what do you do about this, you as a patient do have some options. Whether we as a society have any options in terms of removing excess capacity is a $64,000 question right now. It's actually the $64 billion question.

And the immediate complexity is that it is tied, for one thing, to the labor markets. There are lots of people who are employed and many more in Los Angeles on a per capita basis than in San Francisco in this industry, many of whom are poor and are needing jobs.

There is a question about the equity market. A lot of the L.A. hospitals are proprietary hospitals, Tenet hospitals, for example. And then there is the bond market, like our friends at UCLA have got huge bonds out there. So disrupting this in any way that a market would disrupt it has some very interesting implications.

My hope would be given this — well, put it this way. One possibility, given this, would be that there would be a gradual shift of patients towards more efficient hospitals, either through people like yourself, who make wise choices, shall we say, but also by employers who steer people to them and by this Medicare choice, which is this capitated system, which would love to have this information because now they know where to get their networks designed.

So there is a system within this pay-for-performance strategy that if they were extended to include this level of service, namely supply-sensitive service, you could begin to get some movement.

The loser is going to be Medicare, traditional Medicare, because they don’t do anything about steering patients. And patients who stay at hospitals that are now inefficient while others are leaving it will just get more care because the care will be picked up. And their frequency of those interventions will increase. Yes, that is the problem.

**CHAIRMAN KASS:** Ben Carson?

**DR. CARSON:** Yes. In many of the major medical centers, we were looking at the data, showing that length of stay in the major medical centers and in the regional hospitals might have been approximately the same, the outcome might have been the same.

Does that take into consideration the fact that in many of those major medical centers, there are people who attract the most complex cases that there are in the country and many of the community hospitals and regional hospitals are not dealing with those kinds of patients?

**DR. WENNBERG:** Of course, that's not what I'm talking about here. You would have to say that NYU attracts five times more sick people than Stanford does or UCSF. So, in other words, we're looking here at similar kinds of hospitals.

The interesting thing is that within a market, obviously the academic medical centers are more expensive generally speaking. So in San Francisco, you might think UCSF was the most expensive hospital by our measure. It's not. It ranks about fourth. So there are others that are more expensive. And the ones on the other side tend to be fairly large community hospitals. So there is a difference there.

And if we're going to subsidize academic medical centers to be different because we want them to be different, then that is not what we are doing now. We are subsidizing them. We are paying them because they have — UCLA has a smaller share of the L.A. market relative to its capacity than does
UCSF in San Francisco. And that's the key behind this problem.

There is no question that academic medical centers generally are more expensive, even if they have the same capacity or the same utilization rights because their prices are higher because they're getting indirect medical education and they're getting — well, their disproportionate share in Medicare is about the same, actually. But yes.

**CHAIRMAN KASS:** Paul McHugh?

**DR. MCHUGH:** I very much enjoyed this because it has so many different implications, but perhaps the problem for me — and maybe I just don’t have it yet, Doctor — is that we’re talking about a multi-variable schema of improving the services in care to our patients. We're talking about eliminating underuse, informing, making sure the patients are better informed, and then effectively measuring and managing our supplies. Okay?

All three of them are in play here. In each one of them, no one was going to have any argument that each one of them is good. I mean, we certainly want to underuse effective care.

A condition that I know very well is cystic fibrosis, a chronic condition and amongst children a genetic condition. And it has an ultimate shortening of life. But the length of life that a person has with cystic fibrosis very much depends on what doctor and what center is taking care of them because the centers that do best with these cases are the ones that look after every little nuance of the breathing. I’m not telling you anything that you don’t know, but maybe the others don’t know it.

But if you look after every evening’s sleep for these little children and the atmosphere that they breathe and the moisture of the breath, they live for many years more than if somebody is just dealing with the acute problems that turn up with cystic fibrosis.

And so that is a matter of effective care. And we should be teaching that effective care to everyone who ever takes care of a patient.

Informed patient choice. I mean, that is fundamentally emphasizing the fact that the patients aren’t invalids but are consumers. And consumers have meaning, as you say. And then, finally, there is this management.

But, look, when you have a multi-variable thing that is going to go into outcome— I think this comes back to really what Dan is saying — which one of these things should we work on first to get the biggest bang for the buck as quick as we can because, after all, we have got an expensive health care system and we really want to take better care of patients every day?

**DR. WENNBerg:** Yes. From the point of view of the way the data looked to me, if you want to save money, go after the supply-sensitive. That is what is correlated with Medicare spending.

We have a twofold difference between Miami and Portland, Oregon and Minneapolis and places like that. It’s all supply-sensitive care.

But I say that, and I am going to have to emphasize the difficulty of doing anything about it because it is going to take a lot of societal will to do this.

And I think behind this whole facade here, I mean, behind this whole story, is the fundamental belief that Americans have that more is better. And we’re saying it’s not better. You could give it up, and you could save a lot of money and you could reinvest it in something else, like infrastructure for cystic fibrosis care in the community. That is where we want to go on this.

**DR. MCHUGH:** Well, you know, I am not all that interested necessarily in saving money on this matter, although it is good to save money. I really want to take better care of patients so that patients do better and that patients who come to doctors ultimately, whatever happens, that they do better. Isn’t that the effective care area? And shouldn’t we be working on that perhaps first?

**DR. WENNBerg:** Well, yes and no because the problem is it just depends on our concept of how much more inflation and how much more costs we can bear. There is evidence of marginal harm. So we would want to try to deal with that.

I think the thing that is missing in here is the active engagement of academic medicine in trying to help us understand the scientific basis of managing chronic illness. We just do not have any research projects. The NIH leaves this completely alone. And you can see what it is like.

These places should be embarrassed by their differences, but they are not even aware of them. And
we should try to begin to put pressure on academia to learn how to efficiently manage chronic illness. If we did that, they might begin to respond not only to the specific question about what this theory A does with theory B but also with the whole question about the efficient allocation of resources.

The other thing that bothers me — and I should have mentioned this — is I really don’t understand how in light of this kind of information here, the number of doctors being used by these places — the academic medical centers are out there agitating for increasing the supply of physicians right now. You know, what in the world are they thinking about? They don’t know how many they should use, and they don’t know the mix between primary care and medical specialists.

So trying to get the attention of people to these kinds of statistics in itself might enliven the debate a bit, like it has around this table today, by the way.

CHAIRMAN KASS: Let me have the last, if I might, just very briefly, to try to tie this into some of the concerns that Joanne Lynn raised for us in the last session about end-of-life care.

Really quite striking disparities in the days in hospital and physician visits in the last six months of life, as you showed us here. Let’s assume for the moment that Joanne is right and that you stretch back also since this correlates with the way these people have been treated also for 12 to 18 or 18 to 24 months prior to that.

DR. WENNBERG: You can go further than that.

CHAIRMAN KASS: Right. Let’s assume that she’s right and that looking forward, it’s the long-term care, rather than the acute medical interventions, that make the most difference here.

Is there any way to take advantage of these particular discrepancies and the knowledge of them to begin to fiddle with the incentives? I know you have indicated what some of the difficulties are. It’s the hospital beds that’s driving this. There are bond issues, and there are city employees whose jobs are at risk if one changes this. It’s a very large obstacle to doing something.

Have you thought really about — apart from getting more data and having academic medical centers sort of take this seriously, is there something that the people who now pay for all of this can do —

DR. WENNBERG: Right.

CHAIRMAN KASS: — to begin to shift the incentives in such a way that the services most needful are most available, rather than the suppliers getting their supply houses filled?

DR. WENNBERG: Yes. We thought a lot about that. I have been working for several years now, goes back almost eight years, trying to get CMS to design a demonstration project to allow interested, quality places to experiment with the reimbursement system so they can deal with all of these categories at once.

And we have a consortium that includes Intermountain Health in Utah, Mayo Clinic, Marchfield Clinic, the Hitchcock Clinic, and, interestingly enough, interest on the part of Mass General.

We went to the trouble of getting Senator Jeffords to actually sponsor legislation that is in the ’03 MMA section 646, which asked CMS to do a demonstration project. And we had an idea that we would be doing it, mind you.

That has not happened yet. It’s still hanging up there in CMS space but the idea that the authority is there for waivers to basically pay on partial capitation for managing chronic illness and for implementation of shared decision-making in ways that are not feasible through the fee system so that you could do this without formal enrolling of patients into staff model HMOs, which is very difficult to do.

What we had hoped to do here was starting with places that we were certain because we were already working on these problems, we had encountered severe difficulty with the reimbursement system, to buy the infrastructure, for example, of congestive heart failure and for any of these diseases, that we wanted to have the opportunity to step forward and do this, not because we thought that this was necessarily replicable but, rather, if there were a few good models out there of how accountability across those six points I mentioned to you could be met, then there would be a lot of latitude for figuring out other, more aggressive ways, like selective contracting.

CHAIRMAN KASS: Well, thank you very, very much for an eye-opening presentation, both in the written materials. And there is much to think about here, very complicated.
It does bear upon seeing how some of these built-in structures and practices of utilization really do bear upon trying to do something for the long-term care.

We are running, as is our usual habit, behind. Let's take 15, but really 15. Dan Callahan is here and ready to go. Thank you.

(Whereupon, the foregoing matter went off the record at 3:48 p.m. and went back on the record at 4:05 p.m.)

SESSION 4: AGING AND CARE-GIVING: ENDS AND PRIORITIES IN MEDICAL CARE

CHAIRMAN KASS: While people are returning to their seats, let me just mention that there are a few things that are at your places. Dan Callahan, who will be presenting shortly, has left a couple of sheets that are relevant to his presentation.

I should have mentioned this early this morning, this copy of Cerebrum, which is a publication from the DANA forum on brain science, is here for your interest, but especially here so that you can see how our colleague Paul McHugh has defended the Council's interest in the topic of neuroethics against a distinguished member of the bioethics profession. I'm not sure whether he read the report before criticizing or not but thanks to Paul, and he thought and I think with him that one should see how the conversation that we started continues and I hope will continue further.

The third thing that we have here, Bill, do you want to say a word about that, this article? This is yours, is it not? Am I wrong about this?

DR. HURLBUT: No. I didn't realize that Diane had given it out to everybody. I think this is a very important thing for us to pay attention to because it shows the significance of the integrated organism and its power to reprogram and the potential danger of there being persuasive arguments for actually employing up and running organisms in the production of patient-specific tissue-type organs. I mean, that's maybe stretching.

CHAIRMAN KASS: This is pertinent for the discussion tomorrow?

DR. HURLBUT: Yes.

CHAIRMAN KASS: Okay. Good. I think we are mostly back. The last of our sessions today entitled "Ends and Priorities in Medical Care," we turn from questions of the utilization of the means to a consideration of the ends, the limits, and the priorities amongst the ends.

And we welcome back to the Council an old and dear friend, Daniel Callahan, who, as you recall, was with us — well, the years run together now but at least a year ago, I think, to talk on the research imperative, the subject of his most recent book.

Dan is co-founder of the Hastings Center, was for 27 years its director and president, now is the Director of International Programs.

He has been a rather lonely voice raising the most fundamental questions about medicine and the health care system, about its ends, its limits. Among the books that have tackled these things already 18 years ago, Setting Limits: Medical Goals in an Aging Society; What Kind of Life: The Limits of Medical Progress; The Troubled Dream of Life: In Search of a Peaceful Death; and False Hopes. And it’s I think important that in thinking about these questions at the end of life but in general that we not pay attention just to the economic questions alone but to try to think through what we are trying to accomplish and to look at some of the fundamental assumptions on the basis of which medicine has been proceeding. And Dan has kindly agreed to come and lead us in a discussion of that topic.

Welcome, Dan.

DR. CALLAHAN: Thank you, Leon.

SESSION 4: AGING AND CARE-GIVING: ENDS AND PRIORITIES IN MEDICAL CARE

DR. CALLAHAN: Let me say it is a particular pleasure to be here. Approximately 60 years ago, I was a high school swimmer who swam at the Ambassador Hotel, which is catty-cornered to this hotel, the hotel next to us. And from swimming, I got a scholarship to go to Yale. When I went to Yale, my first course was swimming philosophy. And, hence, many years later, I am back here at the same corner. So that probably proves something or other.
CHAIRMAN KASS: While people are returning to their seats, let me just mention that there are a few things that are at your places. Dan Callahan, who will be presenting shortly, has left a couple of sheets that are relevant to his presentation.

I should have mentioned this early this morning, this copy of Cerebrum, which is a publication from the DANA forum on brain science, is here for your interest, but especially here so that you can see how our colleague Paul McHugh has defended the Council's interest in the topic of neuroethics against a distinguished member of the bioethics profession. I'm not sure whether he read the report before criticizing or not but thanks to Paul, and I thought with him that one should see how the conversation that we started continues and I hope will continue further.

The third thing that we have here, Bill, do you want to say a word about that, this article? This is yours, is it not? Am I wrong about this?

DR. HURLBUT: No. I didn't realize that Diane had given it out to everybody. I think this is a very important thing for us to pay attention to because it shows the significance of the integrated organism and its power to reprogram and the potential danger of there being persuasive arguments for actually employing up and running organisms in the production of patient-specific tissue-type organs. I mean, that's maybe stretching.

CHAIRMAN KASS: This is pertinent for the discussion tomorrow?

DR. HURLBUT: Yes.

CHAIRMAN KASS: Okay. Good. I think we are mostly back. The last of our sessions today entitled "Ends and Priorities in Medical Care," we turn from questions of the utilization of the means to a consideration of the ends, the limits, and the priorities amongst the ends.

And we welcome back to the Council an old and dear friend, Daniel Callahan, who, as you recall, was with us — well, the years run together now but at least a year ago, I think, to talk on the research imperative, the subject of his most recent book.

Dan is co-founder of the Hastings Center, was for 27 years its director and president, now is the Director of International Programs.

He has been a rather lonely voice raising the most fundamental questions about medicine and the health care system, about its ends, its limits. Among the books that have tackled these things already 18 years ago, Setting Limits: Medical Goals in an Aging Society; What Kind of Life: The Limits of Medical Progress; The Troubled Dream of Life: In Search of a Peaceful Death; and False Hopes. And it's I think important that in thinking about these questions at the end of life but in general that we not pay attention just to the economic questions alone but to try to think through what we are trying to accomplish and to look at some of the fundamental assumptions on the basis of which medicine has been proceeding. And Dan has kindly agreed to come and lead us in a discussion of that topic.

Welcome, Dan.

DR. CALLAHAN: Thank you, Leon.

DR. CALLAHAN: Let me say it is a particular pleasure to be here. Approximately 60 years ago, I was a high school swimmer who swam at the Ambassador Hotel, which is catty-cornered to this hotel, the hotel next to us. And from swimming, I got a scholarship to go to Yale. When I went to Yale, my first course was swimming philosophy. And, hence, many years later, I am back here at the same corner. So that probably proves something or other.

The main point, I saw aging prematurely because, like many swimmers, my times went downhill
after age 20. And I sort of jokingly put my head up out of the water and said, "Well, what else is going on in this university?" Anyway, it is a pleasure to be here.

I am particularly pleased that John Wennberg is here because I think what I am going to say shows how one can look at the health care system in an entirely different way.

I have spent a lot of time reading his work, which I have profited from, and reading the work of health economists, epidemiologists, and others who look at the health care system. I come at it from a somewhat different slant. And I would particularly be interested in how John responds to all of this. I will, though, in a way use the economic issue as a point of departure since that seems to me a nice way in.

The national debate on the future of American health care I believe needs to come to grips with the idea and deep value of medical progress and technological innovation. The problem of health care cost increase is an essential issue, and the debate cannot alone be solved I believe by better management techniques or a stronger government or market orientation, nothing less than a rethinking of the ideal of endless progress in health care and medicine will be necessary.

The main focus of my ethical analysis of American health care is focused on the problem of justice; that is to say, how to develop a health care system to provide equitable access to health care and if and when rationing is needed how to do that in a just way.

The justice discussions have long had an interest in the idea of a right to health care or, alternatively, an obligation on the part of government to provide care or for some who like the European way and embrace the notion of solidarity as the foundation for just health care.

Now, it seems to me one basic point that has been missing from much of this extended discussion and debate, I don’t believe it is possible to talk meaningfully about equitable access to health care without an effort to get straight on the goals of contemporary medicine and particularly the way the notion of medical progress shapes and reshapes those goals.

For instance, there have been debates for at least as long as I have been in the field about what is the meaning of the term "medical necessity," which one sees in much legislation, much writing. Like some ancient mathematical questions, nobody has ever been able satisfactorily to pin that one down. So, too, the concept of medical futility, but newer turns out to be equally elusive.

And I think, as you know, from your earlier discussions here on enhancement, the line between medical need and medical enhancement has become increasingly fuzzy as well.

If one uses a sort of pie analogy of justice; that is to say, how do you barely cut up a pie to do right by everyone, the analogy simply doesn’t work in the case of health care because the pie continues to grow. The shape of it is absolutely irregular. And people have different predilections about whether they think it tastes good or it tastes bad. So immediately if you have a simple paradigm of justice, it doesn’t work well in this area.

To me, the interesting question, then, is one of progress and innovation, which it seems to me makes it very difficult indeed to decide what would be adequate and decent access.

For me the problem of properly understanding and deploying technology has become the central problem in determining how medicine and health care should, first of all, set its goals internally toward morally good and economically sustainable goals; and, secondly, how medical progress, its costs and social implications, should be understood in the context of other social areas, such as jobs, education, environment; that is to say, how we compare health needs with other social needs.

Now, a point of departure for thinking about this problem is that of managing health care costs. This problem began appearing with growing intensity in the 1970s, leading to cost increases of 8 to 12 percent a year over a long, long period.

There was a plateau, as many of you know, in the mid 1990s because of the HMOs, but because of patient and physician complaints about actually some of the most effective cost control measures, they dropped many of those measures. And the double digit inflation increased by the end of the 1990s.

Now we now spend, the latest government study, 1.8 trillion on health care, 45 million uninsured, increasing I understand at an approximate rate of one million a year, and health outcomes weaker than many countries that spend much, much less.
The same government study recently estimated there's going to be a doubling. Over the next 10 years, we're going to go from 15 to 18 percent of the gross domestic product on health care. We're going to see a doubling, actually, of the cost of 1.8 trillion to 3.6 trillion in health care costs in 10 years.

Now, to me the most interesting figure is I think the generally agreed upon estimate of economists, that from 40 to 50 percent of the cost increase comes either from new technologies or intensified use of older ones, drug prices leading the way. In general, the aging of society and public demand account together and general inflationary increase account for the rest. But the figure of the cost increase because of the technological factor seems to me the important and interesting one.

There is no end in sight for increases of this magnitude. They're helped along by the great cultural love of progress, the NIH being, I suppose, our great national symbol of a huge investment in research. And I've mentioned earlier in the other session the invocation of a kind of moral obligation to carry out a war on disease.

The rising cost ultimately stems, I believe, from what I call the infinity model of medical progress. That is the commitment to constant and endless progress with no even ideal end in sight or even envisioned. No matter how far one can imagine traveling in space, there is still further one can go. No matter how good health is, there is almost always more to be sought, if only on the frontiers of aging.

Health is a peculiar feature that, however much health improves, the more we spend on it. At the same time as we are worried about health care costs going up, all the statistics show mortality dropping in all the major disease categories and people gradually living longer lives.

Thirty years ago, we spent roughly six percent of our GDP on health care, six percent on health. It's still 6 percent on education roughly, and it's up to 15 percent on health care.

One might really ask, what in the world is going on here? I think while spending on education has remained static at six percent, no one would claim we have a great education at the K.12 level.

Now, it's interesting — and one reason I particularly came at this from the economic angle, I spent a lot of time in Europe. And it's very striking that they're having lots of problems as well. Their problems aren't quite as critical or harsh as ours, but they are worrying about the costs very much. Their cost increases are roughly four to five percent, which is ahead of general inflation. In every European country, their question is, how can we better control costs?

The striking thing is it doesn't matter what kind of system you have, whether it's heavily oriented in a market direction or heavily oriented in a universal care government-run direction, everybody seems to be having trouble these days. So I got interested particularly in what is the common thread in, again, the idea of progress in technological innovations.

Now, we have had a lot of debates on health care. We should look at this particular item in the American health care debate, which is my effort to specify the different levels at which we have debated the problem of health care, particularly health care costs.

I break it up into liberals and conservatives. There's a lot of crossing of the line. So that's a bit crude in many ways. Most of the discussion in our country has been at the level of organization and management. And I think John Wennberg has been one of the great practitioners.

How if we had better change the system can we cope with all of this? Liberals have their whole bunch of schemes. And conservatives have their bunch of schemes for doing so.

I would say that most of the discussion, particularly in the health care journals, is focused on questions of organization and management. And I think this shows a certain American proclivity that we are wonderful managers and wonderful organizers. If we just put our mind to it, we can figure out how to do this.

I guess it's a little bit like saying, you know, "We really won't have any problem going to Mars if we can just have a more cost-efficient NASA and develop much cheaper rockets." Well, okay. That's possible, but I found what is frustrating is the management approach has been going on for 30 years now and it's not clear we have made much progress at all in figuring out better management techniques.

The second level is what I call the government versus the market, which has become pronounced
under the George W. Bush administration. To what extent do we want a government-run system or a market system or if a mixed system, what should be the right proportion?

Interestingly, in this country, a lot of people, like myself, look to greater government assistance in order to get eventually to universal health care, a bit skeptical of the market.

And, contrast, in Europe, they hang on to universal health care, but they are now playing around a bit with the market because I suppose in one sense, if government is finding trouble to pay for health care costs, the market is the only obvious way out of that if you can't reorganize your system to deal with the cost.

The third level is the level I call social values. Liberals like to talk like me, talk about equitable access. I've never liked the idea of a right to health care. There's a lot of problems there.

I've been attracted to the European notion of solidarity, which is a very nice idea if you live in Europe, where people have some sense of solidarity, unlike the U.S., where we are a little skimpy on that. If you look on the right-hand side, if you read the market literature, you will hear lots of talk about consumer choice, efficiency, consumer confronting costs, and particularly the value of competition as a way of controlling costs.

I have a public health level in there because there are at least some people who have gotten very interested in recent years in the socioeconomic conditions between health status, income, jobs, education, and the like, and particularly interested in the problem of how do you promote behavioral change.

Now, this may be just my ignorance, but I don't find comparable conservative literature from a market perspective on the question of the socioeconomic correlates of health status, but I bring this in.

Finally, we come to the area that I think is common to both right and left in that both right and left love the market. The left loves it because a kind of invitation project commitment to infinite progress of all kinds that it is both our right and our obligation and our destiny to keep moving on scientifically and understanding more. And innovation goes with that.

The market is interested because it is interested in satisfying preferences. And you can sell people technologies. They like it. They are willing to pay for it. And, of course, many market-oriented people argue that the market has great side benefits to society as a whole.

The striking thing is that there really is an interesting joining of right and left on the question of progress, from different angles perhaps, but both embrace it.

Now, I think, as was suggested, most of the discussion centers on the top level, with many people believing that good management and organization can solve the problem. And Dr. Wennberg has made a good case that there are lots of useful things we can do.

The one line that gets no discussion at all is the idea of unlimited progress. It, as I mentioned, is shared by liberals and conservatives alike. In fact, I find there is a tendency to want to evade the problem altogether, taking it as a good that requires no defense.

Some invoke a research imperative. We can get rid of these cost problems if we spend more money on research. We will get rid of these expensive diseases or find ways to ameliorate them and, thus, reduce the cost.

There are some that say that we just need better medical and health services research. And Dr. Wennberg echoed that. If we can better understand through research how to run the system and what is wrong with the system.

There are those, particularly one of whom includes David Cutler and now the director — who was the person mentioned? Leon, you had dinner with him last night. Mark McClellan, who really have argued that yes, research and progress do drive up health care costs and, yes, they are responsible for some of our economic problems, but essentially it's worth it because what it ends up doing is saving and extending life. And that itself is a valuable economic contribution. So in one sense, they worry less about what the drive for progress does to the economic side by virtue of its other benefits.

And, finally, there are those who argue, not a few, who basically say, "Well, so what if we spend 18 percent of our gross domestic product on health care? What's better than health anyway?" Not only is it good for individuals, not only does it satisfy most of our preferences to live longer, rather than
shorter, lives, but, again, it has all sorts of economic benefits for society. In other words, what better way to spend their money?

Well, I happen to think that is not necessarily the better way to spend money but in great part because it seems to me there is no good, inherently good, reason why health care as a portion of the money we spend in our society should wildly outrun other sectors.

Now, in putting forth — I will come to what I call sustainable medicine at the end and lay out my specific thinking on some of this, but I think it's important to understand that there are other areas where we have confronted economic problems in a basic way and we really did change out behavior.

We no longer have a supersonic airliner. No company is going to manufacture them. No airline is going to buy them. They decided they were not affordable. And they had environmental problems anyway.

I think we have pretty well decided, despite what President Bush says about going to Mars, that from the future, we're going to settle for space shuttles, unmanned spacecrafts. And, again, it's a budget restraint.

And, finally, my example from my childhood is I grew up at a time when Popular Mechanics and other magazines were projecting automobiles would average 115 miles an hour over these wonderfully engineered cantilevered highways.

Well, the fact of the matter is we don't average driving any faster now than we did 50 years ago. We're not going to get those fancy cantilevered highways. We are all going to have to drive. Probably because of the increasing number of automobiles, it's probably going to get slower and slower, not faster and faster.

So there are other areas that have been important to our society where we have drawn some lines and let the economic realities actually change us.

Some also say when they hear this when I talk this way, "Well, the value is such a fundamental. Not only is it of practical value, but it's so deeply imbedded that I'm looking at a value change which is utterly improbable in our society."

Well, I guess my response is I'm old enough to remember the beginnings of a civil rights movement which radically changed a lot of views on race; a feminist movement which changed a lot of views in the way we should live with women; and, finally, an environmental movement which changed the way we should think about the environment. All of those have their problems, difficulties. None of them have achieved all of their goals, a lot of competition.

But the point is we took things that you would have imagined 100 years ago could never have been changed because they were so deeply embedded. And we did change them.

So what I guess I'm looking for is a new model of what health care should be. And I will give you my own sketch of that. This paper, if you'll take a quick look at that, is called "Competing Models of Medicine." I will just run through it rapidly. I don't think I need to spell these things out.

Model one is the modern, what I call the particularly American model of scientific medicine. Its goal, basic goal, aims for unlimited scientific progress and technological innovation, regardless of their long-term aggregate cost and community impact.

There are no defined finite goals. The aim seems to be a conquest of all disease, one disease at a time; indefinite increase in human life expectancy; relief of all suffering, physical and mental; satisfaction of all desires that might be achieved through medical means.

Medical progress and technological innovation are allowed to set medical goals and to change and redefine those goals, outcomes, considerable medical progress, which has benefitted all of us, and the creation of a massive medical industrial complex.

This model has a powerful bias toward cure, rather than care; acute, rather than chronic, disease; length of life, rather than quality of life; individual benefit, rather than population benefit; technological interventions, rather than health promotion, disease, and disease prevention; subspecialty medicine, rather than primary and family care; and increased medicalization of life and social problems.

The net result is we get unsustainable economic pressure on all health care systems due to aging societies and the increased medical need they bring with them; expensive technological innovations
that bring usually marginal population health benefits only; and an increased public demand as a
result of increasing an often unrealistic public expectation and technological hype with just enough
success thrown in to keep everybody enthused.

I think the major threat to even the possibility of having universal and equitable health care as a
result of this growing number of uninsured I think in the countries that have universal health care a
real threat to their hanging onto it.

Of course, we have a turn to the market by many who are looking to turn to create two parallel
systems of public and private as a way of relieving economic pressure on the public system, which
often results by most evidence, I think, in a widening gap between the public and the private with the
public system losing, expanded out-of-pocket costs for patients, and economic incentives for
physicians to lower the quality of care.

What have been the dominant reform efforts? No interest in changing the underlying mod-
el of progress, innov mains unquestioned, the use of evidence-based medicine, striving for greater
efficiency in health care, economic and market incentives to hold down costs and utilization of
medical technologies and medical facilities, improvement of managed care or other forms of group
practice. And so I'll leave that, the Balanced Budget Act. That was an earlier development.

So here's my model, my alternative model that I call sustainable medicine. And that is a medicine
that is affordable for individuals and economically viable for societies, equitable in the sense that it's
accessible to all and that while there would no doubt be tiers of care, that the gap between them
would not be a damaging or offensive one.

By "sustainable," I mean economically and socially sustainable over the long run, which, in effect,
means that some time or other, we are going to have to become satisfied with a kind of plateau,
where we will more or less level out.

We can't continue in this or any other country increasing the cost of health care well beyond the
general rate of inflation, which means logically, it seems to me, that we're going to have to plateau on
our spending.

This is a medicine to be sustained. For this to work, death has to be accepted as an inevitable and
necessary part of the human condition; some degree of suffering is inevitable; that there is the reality
of human dependency at some time in life; that there is a need for rationing and a dampening of
public expectations; caring becomes as important as curing; — and I am sure you remember Joanne
this morning talked about the great problem we are facing with long-term care and what is going to
happen to the large numbers of people in the years ahead who don't get it — the need to set priorities
in the provision of health care; understanding old age is a time of decline and limitation, open to
amelioration but not elimination; and, finally, a great emphasis on public health programs, the
importance of socioeconomic status, the availability of good primary care as the main determinants
of the health of populations.

In short, a medicine that sets finite goals for itself, being primarily a reduction of premature death,
death itself is not the enemy, only prematurely, big footnote, — of course, you can squabble about
what that means — and that the mission of medicine is set within the context of other social needs,
not assuming a more important or necessarily higher status.

The outcome I would hope if we could come around to that is a medicine that is economically
sustainable. That is, there is more critical thought about what counts as genuinely beneficial
progress, what do we really need as human beings, what can we afford to pay for it, what we really
need, that there will be rationing at the margins, but basically there will be accessibility for all, and
that medicine and health care are understood to exist for the benefit of patients and not as a source
of income or financial gains beyond modest levels and balancing its concerns for the acutely ill and
the chronically ill.

The dominant reform efforts would be to change public perception and understanding of medicine
from one that is inherently progress-driven and infinitely expansive in its aspiration to a model of a
sustainable, more modest, and limited medicine; change the biomedical research priority in the
direction of seeking a more affordable medicine, especially technologically, aiming for a compression
of morbidity, rather than an increased life expectancy; establishing of priority systems for health
care needs, and coming up, in particular, with a more demanding standard of what counts as needs
than I think de facto we have now; and, finally, educate professionals and the public to understand
that equitable medicine will not be possible unless it is a sustainable medicine. Sharply rising costs
will eventually push the poor out of the system, and it will no longer be a viable system.
In short, I believe that if one wants to make a good argument for universal health care, as I think can be made, one at the same time says it can only be done within the context of finite goals, finite ends, and the setting of limits.

Thank you.

CHAIRMAN KASS: Thank you very much.

Michael Sandel?

PROF. SANDEL: Dan, I liked this very much. I’m ready to sign up for your proposal. I have two questions. First, can you give us an example just to make things a little harder for those of us who are taking up your banner? What would be the biggest area of current medical spending that you would on your proposal cut back as not being in line with the philosophy of medicine that you had proposed?

DR. CALLAHAN: Well, I suppose I think John Wennberg very nicely touched on it this morning excessive preoccupation with acute care hospital medicine and trying to persuade people and the evidence seems to have accepted it that more is not better. I think we really believe more is better. So it seems to me the acute care sector is the most costly sector. The acute care sector is where most of the emphasis of the new technological developments come in.

I guess I would also —

PROF. SANDEL: How would you try to talk people out of that?

DR. CALLAHAN: I would start with the Medicare system. And just as now drug companies have to prove safety and efficacy to have drugs released. I would say that the companies should also have to release economic impact statements, what they think their product will do to health care costs, even though a lot of it would necessarily be speculative, but they should do it.

What we get now is basically the market develops a lot of expensive technologies, throws them out the window, and says, “Okay. You people use them. I hope you can find a way to pay for them,” just as in the old environmental days, people just threw their trash in the river and said, “Well, why not throw it?”

And I think that is what the market system does basically with technology. And it knows they’ll sell. It pushes some people like the doctors. There is profit to be made.

So I would really work on coming up with much more. I would also work much more rigorous standards of what counts as a benefit. For instance, in vitro fertilization is a wonderful example because I think the best clinics maybe get a 25 percent success rate. People can go through 3 or 4 cycles at 10,000 bucks.

Now, by any standards, that is a pretty damn poor outcome for an awful lot of money. Politically, though, it’s an item that you can’t go near because people do want babies desperately. But when the debate comes up about whether it should be covered, I would be prone to say no.

A reporter recently called me about an interesting case, whether Medicare, the new Medicare pharmaceutical bill, should cover Viagra. It seemed to me no.

Now, it may be true — I’m sure it is true medically — that some people have erectile problems basically for medical reasons, but maybe you can tease those out but just to pay for it on the grounds that a lot of people want it.

There is a beautiful case of, quote, “need.” Now, do I at 75 need sex or want it? That’s a fuzzy kind of question there. But we don’t talk about that very much.

And do I need expensive surgery, which may or may not benefit me? I might say I need it if I want to leave. I might say I need it, even if the odds are very low. On the other hand, societally we may say we are not going to pay for low odds anymore.

I think, particularly with the elderly, this is where it gets most radical, I suppose, I would say, "Look, beyond 80.85 the standards of acute care medicine and applied technology should be exceedingly high, namely there’s got to be the promise of a really good life expectancy thereafter, at least as good as if you didn’t have the illness in the first place."
PROF. SANDEL: Yes, right.

DR. CALLAHAN: And that would save us a fair amount of money, I think.

PROF. SANDEL: I like all of that very much. I have a broader question, but maybe I will save it until later.

DR. CALLAHAN: Okay.

DR. FOSTER: Let me follow up on a question.

DR. CALLAHAN: Yes.

DR. FOSTER: So I gather that one of the things that you would anticipate doing would be to limit big pharma from developing these drugs that come along.

DR. CALLAHAN: Absolutely.

DR. FOSTER: Now, what do you think the impact would be on the American economy? I know nothing about this, but if you read the newspapers, Wall Street Journal, what happens to the big pharma determines hugely what the outlook is.

And so how far are you going to take it back, just to the generic drugs? I mean, if you are talking about this, you have to be realistic about what it is going to do from all sectors.

DR. CALLAHAN: Well, I guess so. But at the same time, it seems to me that is a terrible trap. One of the things I find strikingly different about the American health care system from the European health care systems is that we talk about all of the side benefits of health care. I don't find the Europeans saying, "We like our hospitals because you get a lot of jobs." We do that in this country. And it seems to me that's very misleading.

I think the net result is that it would no doubt hurt the pharmaceutical industry if we force them to, say, use price controls, as they do in Europe, we force them to cut back on their research.

But I am not sure that it would make any enormous difference in future health if we did so. We might lose some jobs, but we are a thriving economy. Sectors come and go in our society all of the time. We find new things to put in their place.

So I would say sure, it will have some bad effect, but we still will want drugs and we still will want some progress. We will just hold them, I would say, to higher standards than we do now on economic efficacy.

DR. FOSTER: Well, you could stop all the billions of advertising on television a —

DR. CALLAHAN: That would sure help. I mean, actually, direct consumer advertising turns out to be enormously successful.

DR. FOSTER: Let me make one other comment. I almost never talk at these meetings. So I'm talking a lot here.

It seems to be counterproductive to say in some sense that technology, whether it's biotechnology or space technology or whatever, is something that needs to be constrained, instead of saying that this is one of the glories of being humans, whether you're writing music like Mozart or — you know, Richard Feynman said that when he talked about the miracle of the universe and he waxed so eloquently about it that he said it's almost like a religious experience, the late Richard Feynman, the nobel laureate.

But he says — and one of the things that is amazing is this atom, this human, this atom, who wonders and wonders why he wonders but is driven to wonder. I find it very —

DR. CALLAHAN: I guess I would make a basic distinction between what is often called basic theoretical research and applied technological innovation.

I would love to see a couple of billion dollars taken from the NIH and put into astronomy, say, because I think that is fascinating stuff. We're not going to get a lot of money out of doing that, but we are going to understand things.

I would keep supporting basic biological research. To me, the problem is the translation of that research into saleable products is where the problem doesn't come from doing the research and
gaining knowledge per se. The problem is when we try to turn that research into money and cures that then it seems to me one has to set the limit on the innovation.

I think it is wonderful to have developed, you know, the internal combustion engine and understanding how all of that works, but we have an enormous automobile problem in this country. We don't have any contraceptive for it either.

DR. FOSTER: Well, I may have misunderstood. It sounded like to me that you wanted to limit human ingenuity and research and so forth in the interest of—

DR. CALLAHAN: I would limit a lot of the technological innovation but not the basic drive for understanding.

CHAIRMAN KASS: Jim Wilson?

DR. WILSON: Your proposal is one that I do not sufficiently understand. And, therefore, I cannot share Michael Sandel’s enthusiasm for it, but I want to try to gather more information because my enthusiasms are often slowly aroused but when aroused quite durable.

Have you or has anyone who thinks as you do tried to work out the effect on medical costs, the goal now being to cap them at the rate of inflation, of doing such things as restricting acute care facilities or limiting the availability of certain technologies for people over 80 or 85 years of age or other things you have talked about?

These are ideas that are eminently worth discussing, but I have no idea whether they will solve the problem.

DR. CALLAHAN: I must say that I don’t either, but I only propose them because I don’t have any idea whether any of the management changes will solve the problem either. They are at least as difficult to put lots of figures on.

I suppose the point is what I need is for somebody who is in the business of constructing health care systems and running costs to take my idea seriously and use their skills to figure it out.

I must say I don’t know how you figure — knowing in the first place it is enormously difficult to project health care costs and prices, you know, much over five or ten years. It’s a real crap shoot doing this. I would agree mine is exceedingly difficult to do this. But, on the other hand, it seems to me let’s start the work and see if we can figure that out.

DR. WILSON: Well, the point I was making is that this work was started 25 or 30 years ago, when people in this country began talking about finding restrictions and when various states began setting up commissions to discuss, not with any action yet worth speaking of, about how you restrain the growth in health care costs.

And so if in the last two and a half decades, nobody has figured out how to control costs, why are you optimistic that somebody will think of it now?

DR. CALLAHAN: Because I am going at a different level of the problem that has been discussed because everybody took for granted that we needed to constantly be improving everything and having the technology and the innovation.

This is the bottom of my chart. That is the part that hasn’t been examined. The top has been examined like crazy. And we’re still fiddling with that, but the bottom has not.

I want to introduce another angle into this discussion.

DR. WILSON: That angle has been introduced. People have long said that the bottom end of the chart is unmanageable, but nobody has come up with a plan that would contain it.

Now, such plans are available, single-payer, universal health insurance plans of the sort you have Canada or England or Germany. That is one set of strategies. It would be politically difficult, but not impossible, to do that in this country.

Other strategies are to constrain the availability of technology. Another strategy is to constrain the availability of acute care facilities.

What I am suggesting is that you are not suggesting anything new. You are leaving the argument where it was 25 years ago.
DR. CALLAHAN: No. You tell me. I don’t remember anybody in the past saying, "Let’s rethink the idea of progress itself." Limiting the availability of technologies or trying to control the number of hospital beds is not to confront the problem of progress. It’s to confront the problem of how you manage your health care system.

I want to take up the value of progress, which is the one that seems to me to go unquestioned. What you are talking about are various strategies to deal with costs, which touch on it, but they don’t confront it very directly. And, as many people said to me, the notion of where we could constrain progress here, that’s insane. That’s stupid anyway.

CHAIRMAN KASS: I’m sorry. Michael, do you —

PROF. SANDEL: I wondered if I could just help from another angle in answer to Jim’s question. If you tell them you want to be against progress, you’re not going to win his vote, I don’t think.

But, as I understand this proposal here, what is distinctive and what is radical about it is I guess it is sort of at this level or side which you call ideology and culture, which isn’t only about progress.

What you are saying is — do I have this right? — you want to change the culture and the ethic that lead us to consider — that causes health to loom so large an unquestioned good that it has a kind of endlessness, endless in the sense that we don’t deliberate about what the point or the purpose of health is. And so it’s an unbounded goal or aim because we don’t ever reflect on what a good life consists in as a way of delimiting what counts as health.

DR. CALLAHAN: Right, yes.

PROF. SANDEL: Do I have that right?

DR. CALLAHAN: I think that is absolutely right. And one thing, again, I find striking in Europe — one thing I ask people a lot, "How much attention is there paid in the media to issues of health, technology, and medicine?" It’s strikingly much less. It varies from country to country, but when I mention, say, The New York Times has five or six reporters who do nothing but report on health care and stuff gets on the first page, this is much less the case.

There does not seem to be a kind of obsession with health and health care that there is here. People like good health, but as somebody from the Czech Republic said to me a few years ago, "Let’s talk about end-of-life care," and the answer was, "Well, people get old and die. What’s the problem? Why do you Americans fret so much about this?"

I must say, "Well, okay. This is a different culture." Now, that —

DR. FOSTER: That’s not new for you because a long time ago you constructed a system of contrast, which was, I think you called it, the power/plasticity model, as opposed to the sacral/symbiotic model that —

DR. CALLAHAN: You really go back a long way.

DR. FOSTER: Well, I remember things.

DR. CALLAHAN: I had forgotten that.

DR. FOSTER: I remember things, yes.

DR. CALLAHAN: But it sounds good.

DR. FOSTER: So his idea in the power/plasticity model was that because we can keep people alive a long time we ought to do it, while in the sacral/symbiotic model (which he preferred) we accept death as natural, not always to be fought. So you have been thinking about that a long time.

On the other hand, I still remember Malcolm Muggeridge’s famous statement a few years ago when the U.K. system decided that above the age of 65, you would not be resuscitated. So it had NTBR (Not To Be Resuscitated) on your little card there.

When he saw that, he didn’t know exactly what that was. And when we found out it meant that, although he was a vigorous 65, that if he should have sudden death, that he was not to be resuscitated.

So there is sort of built into this — I don’t know whether 85 is a year or what, but most people, you
know, still would like to keep — if their health is good, they actually —

**DR. CALLAHAN:** What Great Britain did in the ’50s and ’60s was there were informal limits, particularly on dialysis.

**DR. FOSTER:** They had no dialysis. Thirty-five hundred people a year died because they didn’t —

**DR. CALLAHAN:** But the point is it was never official policy. It was done by a sort of practice, and it was covered up by calling it it wasn’t medically indicated if you needed dialysis and the like. But eventually they changed that because of public pressure.

I guess the point is it seems to me that was the same with medicine. You’re going to have to make some hard and nasty choices somewhere or other. I mean, to me what is going to happen?

We’re soon going to get an implantable artificial heart. It’s going to be very effective probably in saving a lot of lives of people over the age or 85 or 90. It’s probably going to cost a couple of hundred thousand dollars to implant, $25,000 a year to maintain.

Ought we do that? If we don’t do it, they’re going to die. Should we do it? And where do we stop this? On and on and on, it seems to me.

I guess I would take a view I sort of still believe in a kind of natural life cycle, that it’s okay to get old, we don’t have to fight death at the age of 95 with heart transplants or open heart surgery.

Now, you might say to me, "Well, you haven’t been tested. Let’s see what happens." Well, we’ll see what that time comes. But I can’t imagine having a health care system that is eventually affordable in the long run without saying there are certain things we simply cannot afford to do because if we do them, we’re going to have to take some money from other areas of society that are very well.

I live in New York City. If you need a heart transplant and at least if you can get the organ, the government will pay for it in fancy hospitals with highly paid people. Two blocks away, we’ve got the high schools that are lousy, overcrowded, buildings falling down. Then you have to say, "Well, is this the right way to spend money in a society?" I’d like to see that kind of question.

An issue that doesn’t get much discussed is how we want to balance the different sectors, but I think in the end, any limits you suggest, somebody is going to say, "Well, it’s murder. It’s killing. Isn’t that awful?"

But, on the other hand, if you have increasing health care costs, one effect of the increased health care costs is companies are cutting back on their benefits. The number of companies that provide health care benefits are going down or they’re cutting it at family members. You really get a lot of lousy fallout from these costs.

**DR. FOSTER:** I’m not against the sacral —

**DR. CALLAHAN:** Okay.

**DR. FOSTER:** — at all. I think it’s a wonderful model. It’s just the question is, where is premature death? I mean, if you were to die today, you say, "Well, okay. I’ve reached beyond the three score and ten, but I still think I have something to offer." And as a consequence, I would think it might be premature if we had something that we could save their life and so forth.

**DR. CALLAHAN:** Well, I would say fine as long as I feel I’m not taking resources from the young taxpayers who would be paying my Medicare bills and could not bear this burden without hurting their own lives. That would be my standard.

**CHAIRMAN KASS:** Dr. Wennberg?

**DR. WENNBERG:** Sorry to join in, but since I’m down in level 1, I wanted to have a chance to —

**DR. CALLAHAN:** Thank you. That’s —

**DR. WENNBERG:** I think that, Dan, it seems to me that the level 5 statements here are confusing to me because I think that you and I have a different opinion about when progress has happened in medicine.

So that what I would like to see at level 5 is a skepticism about manifest efficacy; in other words, the belief that if it happens, it’s good for you because it’s medical care so that and we ought to do that
both with our physicians to make them more skeptical about theories and more willing to investigate
them because I am quite certain that things that you mentioned about being medical progress are
probably going to be very problematic when you look carefully into who gets it and what the
outcomes are.

We’re actually doing some work right now with bare metal stents versus the drug-eluting stents. And
it’s not as good as it sounds maybe. We don’t know yet.

The point is that carefully looking at technology in a post-marketing surveillance sense creates the
information that essentially would feed skepticism.

I mean, Vioxx was hugely skeptical, skeptic-producing. And so a more sophisticated attitude
towards technology and a more sophisticated attitude towards progress — I mean, I think progress is
great. We just don’t see too much of it. And your list is kind of progress, but it isn’t really.

And so becoming more sophisticated in terms of our demands for evaluation and assessment and,
yes, cost-benefit analysis and then taking that information into a much more public debate would
maybe get us to where you want to go because I think you want rationality. I’m not sure you need to
do that through rationing at this point, but maybe you do.

To me, there is an awful lot of excess capacity in that acute sector. And there is a lot of surgery being
done to people who don’t want it. And you want to take that into account and fix that problem along
with the societal problems because the fixes for those two problems actually involve significant drag
in terms of the current perceptions of what goes on. The role of the patient in discretionary surgery,
how to act on that, how to finance that, that is a big deal, and also how to deal with that excess
capacity problem in the acute sector, which I think most people recognize now.

It’s not a big mystery anymore, but it is a question about how do we begin to deal with “You can close
anybody else’s hospital but not mine” or “You can put pressure on this”? Those are pragmatic
political questions. Getting that skepticism into place I think would be more likely than having a
debate about whether the enlightenment was really worthwhile or we’re believers in infinite progress
when, in fact, there’s not —

**DR. CALLAHAN:** Well, let me give you sort of one question back to you. It’s very possible that
everything you suggest will forestall the day of reckoning where we find we have done all of that and
here we’re still — that’s very possible, that day. And then maybe the day will never come, but my
guess is at some point in the long run, what I am saying will be true. It will not be possible to keep
indefinitely trying to keep people alive and by virtue of evidence-based medicine finding a way to pay
for it.

I guess, secondly, with evidence-based medicine, I am struck by a point that does not seem to get
touched on very much. You have pointed out, in some hospitals, under-treatment. We’re finding
out that only like — I forgot the exact figure — 50 percent of people who should be taking high blood
pressure are taking them, only 50 percent of the people being treated for cholesterol. This is
evidence-based medicine telling us we should be spending more on things.

I think evidence-based medicine turns up as many things that we should increase our spending on as
on things that we can cut back on because they’re not efficacious. So I see that as a two-edged coin.

I guess I am struck by the fact that when I look at the European systems, they’re having trouble, too,
though they actually do a lot better on many of the things you’ve mentioned than we do. But, even
so, they are straining.

But let me ask you the short term versus long term. Do you think what you are suggesting will be
work indefinitely long into the future to keep us from having to rethink progress?

**DR. WENNBERG:** Well, I guess I would say I don’t know because I can’t predict the future, but I
would say that the basic scientists feel they can save us from ourselves by coming up with cost-
effective treatments that require very little of what Lew Thomas called intermediate technology. So
it’s probably just as well to bet on that as it is on the idea that something will come along.

They sure haven’t succeeded in the history of NIH in doing that, though.

**DR. CALLAHAN:** They also haven’t succeeded in evaluating what they’re doing.

**CHAIRMAN KASS:** Let’s collect a couple of questions. Then Dan can take them together unless
there’s a kind of dialectic development in which people can jump in.
Robby George has been waiting and then Frank.

**PROF. GEORGE:** Thanks, Leon.

Dan, I think I understand, although if Jim Wilson says he doesn't quite understand, then I'm sure I don't understand. But even understanding as I think I do, I can't quite share Michael Sandel's enthusiasm. I think I agree with the sentences beginning with even numbers and disagree with the sentences beginning with odd numbers, but there is much wisdom there.

Two questions. First of all, the point that you made about the Europeans' comparative advantage over us on the question of commitment to solidarity, we can quarrel after the session about whether that is in the end true.

I was wondering what you were using as a measure. Was the measure of that simply the question of the social provision or the governmental provision of social services or would you be prepared to defend when we do argue about this?

Would you be prepared to defend that in more general terms, the Europeans when it comes to charitable giving and the range of other things that we might factor into any assessment of comparative commitment to solidarity, that the Europeans would still be dramatically ahead of it?

**DR. CALLAHAN:** Well, I would say certainly in the area of health care, the dramatic — they look upon health care as a simple moral proposition. All of us are equally subject to illness and suffering, and we should support each other in that mutual thread. That's the notion of solidarity. We are humans who are in this common situation.

In fact, in this country, we already have a common notion of solidarity. We have it in solidarity in fire departments. Everybody agrees there should be basic fire departments. You may buy extra, but we are all going to get fire protection, regardless of whether you live in a brick house or balsa wood house.

We also believe in common police protection. Again, it's a notion of solidarity. They put health care in the same system in the same kind of context. This is that we all share a problem and, therefore, we should pay and support each other for particularly health care, which is very expensive.

So I think it's interesting. It really goes back to Leo XIII and papal teaching, interestingly enough. That's the historical origin of that. It's a very communitarian notion of what it is to live together in a society.

They do believe that, of course, a heavy dependence on government. They don't have the nasty view of government that we do in this country. Unfortunately, you know, they happen to get better health outcomes as the bottom line for all of these values.

**PROF. GEORGE:** But there could be a range of reasons for not going for the kind of health care system that you have that don't have to do with the rejection of solidarity as a principle. You could believe that it wouldn't work very well, it would be counterproductive. There's just a whole wide range of —

**DR. CALLAHAN:** The only alternative to a government system is the market. And the market is not big on solidarity. The market is big on satisfying preferences and self-interest. It is not interested in community.

**PROF. GEORGE:** But you wouldn't want to jump to the conclusion that every time we go for a market solution over a governmental provision solution, that must reflect a lack of a commitment to solidarity. That would be —

**DR. CALLAHAN:** Well, no. Actually, I like what the Europeans are doing because the Europeans hang on very much to solidarity, but they do a lot of market experimentation. But they say our core value is that we are going to continue providing access.

We are going to see if the market can help us control the costs a little better, get a little higher quality. That seems to me a very good use of the market, but their basic commitment is we are going to make sure everybody has pretty good access.

But we're going to try to use the market to improve the system. So it's the use of the market within the context of universal health care.

**PROF. GEORGE:** Okay. Well, we can have one of our arguments about this off record.
The second question I had was something that you said that I found very interesting and provocative, so much so that I wonder if it was a slip of the tongue or if I misunderstood you.

Down in level 5, Dan, when you were in ideology and culture, you said or I thought you said that both sides love the market, both the left and the right love the market. Did you mean that or were you saying that both the left and the right love progress?

**DR. CALLAHAN:** No. I'm sorry. Both the left and right love progress for somewhat different reasons, though.

**PROF. GEORGE:** Yes. Okay. I wondered whether you had in mind the British Labor Party and the New Zealand Labor.

**DR. CALLAHAN:** No, no.

**PROF. GEORGE:** No? Okay.

**DR. CALLAHAN:** No, no.

**PROF. GEORGE:** So it was just a slip of the tongue?

**DR. CALLAHAN:** Yes.

**CHAIRMAN KASS:** Frank?

**PROF. FUKUYAMA:** Well, Dan, I'm quite sympathetic to the analysis in the following sense. It seems to me there has been this unacknowledged down side to technological progress that was made very clear.

I missed Joanne Lynn this morning, but I heard her when she briefed the staff of the Council. From that, it just seemed to me very clear that the cumulative effect of a couple of generations of biomedical progress was to allow people that would have died relatively quickly and at low cost to the rest of society from a heart attack, you know, allow them to spend ten years in slow degeneration at extremely large costs to society.

You know, this was a big elephant in the room that nobody was willing to acknowledge that, you know, perhaps there actually not only hadn't been progress but we in a certain sense left ourselves worse off.

But it does seem to me that this proposal, even if you acknowledge that, is awfully hard to implement and particularly awfully hard to implement in the United States because you really do have to abolish the market, I mean, completely.

If you allow the market to operate, there are so many people out there that will want these services that they will simply get them from people that are perfectly willing to provide it. So you have to go to a state-run single-payer system that is actually much more draconian than any of the ones that exist in Europe now.

And all of those European systems are, as you suggested, under tremendous pressure to liberalize their criteria for rationing medicine because their publics really want this stuff.

The other thing is that I am not sure that this is the right place to freeze progress because this is the wrong plateau. I mean, if we're really on this plateau where everybody is going to require ten years of dependent care, that's not such a great place to end progress.

And so I guess it just seems to me that all of the political pressures are pushing in a very different direction, particularly here in the U.S. I just don't see the political feasibility of this.

**DR. CALLAHAN:** Well, it's very interesting. There seem to be different views of where things are going. There is one view of some recent studies published in Health Affairs to say that a lot of people are getting suspicious of going more in a market direction. I was thinking maybe we're going to have to go back to government. And, actually, the study I mentioned by the Medicare/Medicaid department said we're going to go up to around 50 percent of government spending anyway.

I think your interesting point about the slope of progress was about all this. I guess the question is, it seemed to me, at least for a long time, that there has been excessive optimism about being able to overcome the diseases of aging.
When we got started, Leon will remember Lewis Thomas, I think somewhere around the mid 1970s, a great medical writer, said, “Well, in my generation, we have seen infectious disease overcome. Before I die, we will also see the chronic and degenerative diseases of aging overcome as well.” Well, he died of cancer some 25 years later.

Things are getting a lot better, but the point is, I think, as Joanne showed very nicely, if there are statistics, we are pushing disability back to a later stage of life, not getting rid of it.

To me, I find it a tragic dilemma in a funny way that it would have been better if I had died at 65 from a heart attack than now die at 85 from chronic congestive heart disease, which is a lot lousier. It's slow, and you can't breathe and drags on and on. And then if you're around a little longer, you're probably going to get demented, too. Is this progress?

The point is we're not doing terribly well, it seems to me, in dealing with these diseases, despite the optimism. So I don't know where to stop. It might be that if we keep going, we could make things worse, as we have done in the past. We have made it worse, not better, in some ways.

CHAIRMAN KASS: Gil, Peter, Janet, Paul McHugh, and myself. Then we'll probably be at the end.

PROF. MEILAENDER: Dan, first, insofar as what you're really after is a deep cultural shift, I have to say that I think there are other institutions to which you need to devote your attention if you want to accomplish that. We don't get that by writing books.

I just found myself wondering, what if we did the same sort of analysis somewhere else? What I mean is, there would be another way to get the money for those high schools that are so impoverished and give such lousy education.

Sort of closer to home, what if we asked similar questions to the kind you ask about the higher education system in this country? Couldn't we do all the same sorts of questions? How do we decide whether places are permitted to create new programs and hire new faculty? How many colleges in the country in recent years are adding programs in meteorology and communications so that we're going to be a nation of weather reporters finally?

You can hardly go on a college campus where there is not a new science building going up right now. Colleges compete to advertise how well.wired they are, why didn’t we freeze that 25 years ago? Were our students learning more now than when they browsed the journals in the library? Should we increase teaching, double teaching loads, say, and cut back —

DR. CALLAHAN: I know the answer to that one.

PROF. MEILAENDER: — cut back on leave policies? I mean, it’s a whole similar range of questions. It’s the same kind of analysis. It’s not clear that we’re better off because of our commitment to sort of endless what we consider progress in the academy. And I don’t think that being badly educated is any better than being unhealthy.

It just seemed to me that the kind of analysis you're doing could apply in all sorts of —

DR. CALLAHAN: Well, I totally agree. As a matter of fact, though I don’t teach and have never taught in my whole career and didn’t want to teach and didn’t want to be in a university, I subscribe to the Chronicle of Higher Education if only to see what is going on.

I think the critique is just absolutely of all of the major institutions, all need this kind of critique. They will take a different form because they have different sorts of problems, but nothing I am saying about what we need to do in health care is meant to imply we shouldn’t do it everywhere else that seems to need it also.

PROF. MEILAENDER: I understand that, but what I am suggesting is that, even though you can find all sorts of absurdities and I have actually named a few of them that I regard as that, we don’t, in fact, think that the way to solve that problem in the area of education is a way that would be analogous to what you are proposing with respect to health care.

Now, maybe you think it would work, but I don’t think —

DR. CALLAHAN: Well, I guess I would like to see universities — I mean, you are mentioning they are all putting up new science buildings. I mean, they're not putting up big new philosophy departments. That’s for sure.
And it seems to me that everyone might well ask, is that what this society needs? They're putting them up because there's money in science. There's not money in philosophy in the English literature and things of that sort. But everyone can ask, what do we need from higher education? Do we need more science buildings or more of a lot of other things it seems to me a lot of analogous sort of question.

What are the proper goals of higher education: to turn workers' jobs to make money for the university, et cetera, et cetera, et cetera, or what?

PROF. MEILAENDER: That's fine. You're a man of perfect consistency here. It just seems that buried somewhere there is an enormous confidence about our ability in macro ways to figure out what actually constitutes progress and would be a good thing.

DR. CALLAHAN: Well, I think it's terribly hard. I would like to see it discussed at least, though. I mean, it's interesting. There's been a slate of books and articles that being richer doesn't make you happier. Getting all you want doesn't make you happier. A lot of progress creates as many problems as it solves.

So I think there's sort of an interest in looking at all of this stuff all over the place, particularly the notion "Gee, we are a rich and powerful nation. Why are we so unhappy?" That's a theme one can find around these days.

So do we really have a disagreement here? I'm saying sure, it's very hard, but so what?

PROF. SANDEL: If you don't, Gil's about to make a brief for unhappiness.

PROF. MEILAENDER: No. I just think that at the bottom, you are a religious thinker. That's, of course, not a criticism when I say it, but that's the kind of analysis that you're actually providing and —

DR. CALLAHAN: No. I'm a liberal who would like to see liberals deal with the kind of questions that religion deals with in a better way.

PROF. MEILAENDER: The malady that you discern requires a solution that goes deeper than any you can offer.

DR. CALLAHAN: I find the enthusiasts for technological medical progress seem to be as deeply embedded in religious communities as nonreligious. I don't see that makes a hell of a lot of difference, frankly.

I mean, I know a lot of people who would say what I am doing is proposing that we kill people. Somebody said, "Callahan, this is social euthanasia. There are people who are going to die if they listen to you." Well —

PROF. MEILAENDER: You want to teach us to think differently about our desires.

DR. CALLAHAN: That's right.

PROF. MEILAENDER: Okay. And what I said is that is an illness that goes deeper than any solution you've offered can deal with.

DR. CALLAHAN: Well, I agree it probably is.

PROF. SANDEL: Yes. Embrace that, Dan. Don't shrink from that.

CHAIRMAN KASS: Your solution is not a religious one.

DR. CALLAHAN: I'll fill in all the details of how to do it.

CHAIRMAN KASS: Let's go. Peter Lawler, Janet, Paul.

DR. LAWLER: I agree with what has been said. What you have here is a broad side against the American way of life. So I agree on your list of powerful biases you lay out here are powerful biases, but I see you have seven of them.

You must be some kind of Straussian because the one in the middle, number 4, is individual, rather than population, benefit. That is, we consent to government as individuals. I can't be used for the population. I'm not a bee or an ant.
Now, if that’s the case, I think you might ignore the noble side of this way of thinking about things, which can be stated along these lines: intrinsic dignity of the individual or something like that.

And the other great movements you talked about, like the women’s movement, the civil rights movement, and so forth, were on behalf of individuals, lifting them up or out of artificial constraints.

And maybe an unsustainable side, I have to admit, of a country devoted to individuals, that side is unlimited technological progress because technological progress is clearly a benefit to individuals.

So it seems to me there is also something connected with allowing technological progress to be limited on the side of equity. For example, isn’t there something noble about the American impulse we have talked about? As soon as dialysis is available, the American impulse is to say, "Everyone gets it." That may not be sustainable, but that is still noble in my opinion.

There may be something bad about the fact that not everyone is covered by insurance. I have to admit, but the consequence of saying IVF is not covered by insurance, I’m not even for IVF. Nonetheless, rich people will still get it. All you’re doing is denying IVF to the poor. All you’d be doing is denying dialysis to the poor. Rich people will still get it somehow and the same thing with Viagra and all the other things that were mentioned.

So my criticism or what I would like to hear you talk about is aren’t you kind of setting up a straw man here by not talking about the noble side of a country devoted to the individual?

DR. CALLAHAN: Well, I guess it’s a matter of how much is enough, how far do we want individualism to go? I think I’m properly — someone characterized me as I’m a communitarian. That is to say, my first question is what is for the benefit of society?

And I’m a kind of Aristotelian. We are not isolated individuals. We live in a web of other individuals. And my individual good or bad is going to impinge or affect other individuals.

There are plenty of wonderful things in the individual. In fact, it’s not hard to list them, but I think have we reached the saturation point. I think it’s wonderful that people have automobiles, but have we reached the saturation point of how many automobiles we can tolerate on the roads in our — I live where everybody spends hours in traffic jams all the time.

I say all right. It’s wonderful to have this individual right, but collectively whether it’s doing us much good begins to be open to question.

DR. LAWLER: So you’re for individual rights and all —

DR. CALLAHAN: Oh, sure, absolutely.

DR. LAWLER: You’re just against the excesses?

DR. CALLAHAN: Absolutely. That’s a nice way to put it. And the question, though, is when do you reach a point of excess? And how do you know it when you see it or have you been so brainwashed you’ll never know it when you see it.

CHAIRMAN KASS: Janet Rowley, then Paul McHugh?

DR. ROWLEY: Well, contrary to Michael, with whom I almost always agree, I am very troubled by your presentation today. And maybe it’s because of my close connection with oncology.

We have used the information that has been gained over the last decades, particularly in understanding the human genome, to make enormous progress in developing drugs that can be remarkably effective in treating patients, some patients, with cancer.

For example, patients who have chronic myelogenous leukemia, now a high proportion of them can be treated and often, if not cured, at least have very, very long remissions due to Gleevec or Amantanib. There are a number of others of these that are coming down the line that are going to be very effective.

So saying that we should shut off medical progress now and that implying that it’s only just for doctor self.amusement or scientist self.amusement that these things are being done I think is a real distortion of that.

DR. CALLAHAN: I don’t think in my outline I talked about scientific doctor self.amusement? I don’t believe I did.
DR. ROWLEY: You don’t, but you take medical progress and say, "Is it really progress?"

DR. CALLAHAN: I don’t. I would —

DR. ROWLEY: I think that that is just a dreadful point of view.

DR. CALLAHAN: Well, I would take your field of oncology as a wonderful example. I would say with new proposed treatments with chemotherapy, radiation treatment, that the standards of accepting them and paying for them should be very high, a short time of life expectancy would not be good enough to qualify.

I’m not for stopping the research. I’m saying let’s make sure when we begin applying the research, that we are very demanding in what we will accept as a good outcome. That’s all. That’s not to be anti.progress.

DR. ROWLEY: Now, aim for a limited scientific progress. And where do you decide what progress is okay to pursue? And which ones should you abandon?

I think this is a really terrible way to look at a very difficult problem, namely health care costs and their increasing health care costs and the inappropriate use of some medical services in various categories of disease.

DR. CALLAHAN: So are you saying we shouldn’t have this discussion at all?

DR. ROWLEY: Well, I think that the point of view that all of our problems or many of our problems are due to the hubris of scientists wanting to have studied things —

DR. CALLAHAN: I don’t believe —

DR. ROWLEY: — and have progress, regardless of what the outcome is and regardless of what the cost is, I think is not the appropriate focus.

DR. CALLAHAN: I didn’t say individual scientists. I said the enterprise.

DR. ROWLEY: But the enterprise — science only goes forward with individual scientists. This is not something on high that people are doing. It’s the individual that contributes to the progress. So it is us as individuals that I think —

DR. CALLAHAN: But it has —

DR. ROWLEY: — could be interpreted as being the focus of this.

DR. CALLAHAN: Well, I think there is a culture. There is a culture of science, which has once unlimited technological innovation, which, again, is different from unlimited scientific knowledge.

DR. ROWLEY: But you lump them together here.

DR. CALLAHAN: No. In answer to one of the other questions, I separated them. I said they are different enterprises, it seems to me.

CHAIRMAN KASS: Paul?

DR. MCHUGH: Well, thank you very much, Mr. Callahan, for coming because, as you know, I have been listening to you for about ten years. At first, I just thought you were perverse. Now I think you’re just out of date.

I agree with Janet and Peter and very rarely again disagree with Michael. But, look, there are aspects of the things you are saying that are really quite paternalistic and puritanistic, too, in a patent way.

Fortunately, this time we had your paper to study before we came. I had a good chance to read over it. And although you didn’t present this paper and I’m not going to quite comment about it, I have to say that I have heard this kind of stuff before, particularly ignoring the fact that he who defines need makes a political decision and exercises power over those who depended upon the decision.

Here in America we think that people ought to vote on what we need and ultimately see how what we want develops out of what is available to us.

You know, as I was reading your stuff, I kept thinking the ghost of Beatrice and Sidney Webb was
just floating through all of this with their beliefs that individualism in competition ultimately leads to anarchy of some sort and the anarchy here of costs. And it's to be combatted by centralized authority and oversight committees of experts that will bring social discipline to all of us.

I just want to ask you whether that is a correct thing. Gil calls you religious. I think that in various places of the world, where we are trying to provide care for those who can't afford to pay for it but ultimately insist, in some way or another, those who can pay for it do so, is the aim that we are going towards. And that permits us to be both progressive and developing and optimistic about the future and presume that we're going to do better than we're doing now.

We heard from Dr. Wennberg that there is all this excess capacity. I think we should employ that. Tell me, are these your forebears? Do you live with Beatrice and Sidney Webb and all of their loves?

**DR. CALLAHAN:** First of all, my argument at this level has nothing per se to do with government. First of all, just a little footnote, for 30 years now, public opinion survey said a majority of Americans would prefer universal health care in this country. That's been talked about. Consulting the people and their view of the needs, I believe that's true, Dr. Wennberg, that surveys have always supported universal health care.

Secondly, I don't believe in decisions by expert committees. I believe in public decisions. This is a committee that has got a few people who are experts in bioethics, but it's got a lot of other people. That seems to me the right kind of committee. It seems to me these issues —

**DR. MCHUGH:** I don't see how these kinds of things are going to be decided if you don't have certain experts that are going to tell us all how we should live, what we should have, what Janet should work on, those kinds of things, and what should be available to us, whether it be Viagra today, IVF tomorrow, or something else. It looks to me like you are determining for us what we should need and we ought to keep those needs under control because —

**DR. CALLAHAN:** Well, I'm saying —

**DR. MCHUGH:** — daddy knows best or —

**DR. CALLAHAN:** Well, I don't —

**DR. MCHUGH:** — daddy, not big brother.

**DR. CALLAHAN:** I think this is a total parody of what I said. And so I don't think I said any of that in any case. You see, this is the problem about talking about progress. Everybody feels terribly threatened. And, by God —

**DR. MCHUGH:** I'm not threatened. Keep the psychology out of this. No, no, no.

**DR. CALLAHAN:** They're going to drag their old dead horses into the discussion now.

**DR. MCHUGH:** Listen, I love it when you bring in psychology to psychologists. You know, every interpretation is hostile, Mr. Callahan, and I don't have to put up with that either.

**CHAIRMAN KASS:** Gentlemen, gentlemen. Let me have a try and since I think I have had some sympathy for just about everybody who has spoken here, which means that there is something about the way in which Dan has presented this that has produced a certain kind of polarizing reaction.

People are, as I know better than most people, generally responsible for how they are misunderstood. Nevertheless, we should do our best I think to try to separate out what has been said here that is I think worthy of our attention. I will do this partly I think coming to your aid and also partly, I think, raising some difficulties.

It does seem to me that it is good of Dan to raise the question about what are the goals, what are the implicit goals, of the way in which we are proceeding. You can raise that question without attaching the slogans of are you for or against progress or are you for or against death or are you for or against the enlightenment.

We have a system which has been operating under certain kinds of tacit assumptions. It looks as if we are behaving as if we believe the goals are right. We are not just getting there fast enough. And the more there is, the better.

Wennberg at least raises the question as to whether more really is better. And that, of course, raises the question of, what do you really mean by better and how do you know whether you're going
forward or backward with respect to the goals that you do have?

And then Dan wants to raise the question about whether or not these finite, these not defined goals that we have under the modern particularly American model are reasonable. He lists five goals.

And it’s a perfectly reasonable question to ask not of individual scientists and not even of the scientific establishment but to ask the society as a culture, are these goals to which we subscribe? And does it make sense to commit oneself to those goals as if one had infinite resources and infinite capacities and what it would mean to commit yourself to those goals, rather than to the goals, for example, that Janet is frequently reminding us of in the other discussion, the question of care for children and not only of the health care of children but I assume their education and their general nurture and well-being.

So I think that we should welcome, we really should welcome, the opportunity to have a look at the question of the tacit goals of this enterprise. That would be one point in Dan’s favor.

I am struck, Dan, however, when you come to the Callahan model of sustainable medicine. The goals that are given are not medical. The goals are things that have to do with affordable, equitable, and sustainable. And that is not so much answering the question of what is medicine really for.

That’s a question of the system and whether people are going to be able equally to have access to it, whether we’re all going to continue to pay for it.

Those are important questions all, but there isn’t a symmetry here. The current system you say has as its tacit goals the conquest of all disease, the indefinite increase of life expectancy, the relief of suffering, the satisfaction of desires, et cetera, et cetera. The question is, what is Callahan for?

As a goal of medicine, as opposed to — one of the reasons why you pick up the vote of Professor Sandel is he is I think, in a way, less interested in the intrinsic question of the goals of medicine or at least as much interested in the kinds of questions of social solidarity, equity, and questions of justice which —

PROF. SANDEL: No, no. The whole point is that they go together.

CHAIRMAN KASS: Fair enough, but Dan hasn’t really I think sort of put forth the goals of medicine as such, which would be reasonable goals.

The reason I think that is important to do is because, as has been said — I mean, Peter Lawler tried to put this in terms of our attack on segregation and discrimination against women was in the name of individuals, but I would have said that those are also attacks against certain kinds of evils that it became increasingly hard to defend those evils.

Here what you are really going to be mounting a case against is the desirability of long and healthy life. And there are not a lot of votes for that. I mean, the change of the culture on this score is a very different kind of change.

I think you have to try to articulate the kind of goal of medicine in a culture in which the successes of medicine have not made people more inclined to disappear. On the contrary, they have led us to hope and not unreasonably that there will be a cure for Alzheimer’s disease and that, rather than accept these ten years of debilitation, one should let Dr. Sellcoe and his colleagues loose to look for a vaccine or whatever it will be.

I mean, it’s a kind of endorsement of the question, plea for a certain articulation of these goals and to do so with the full recognition that individuals die. And they might be inclined to die for their country, but I don’t think they’re going to be inclined to sort of step aside and forego various kinds of cures for themselves and their loved ones for the sake of some kind of abstract notion of sustainability.

DR. CALLAHAN: May I respond to that?

CHAIRMAN KASS: Please. I’m done.

DR. CALLAHAN: First of all, let me respond, as many authors do. I’ve addressed all of those issues of specific goals in another book. My last book on the research imperative ends by specifying goals. I said a good way of specifying medical goals is to do it by age group. And I tried to do it briefly for children, adults.

And I have written numerous articles on appropriate medical goals for the elderly. I’ve also written in my book False Hopes that I think the way to go for this healthy life is through the route of
behavior modification, behavior change, public health and prevention and socioeconomic change because statistically those are the things that make the greatest difference in the population health, not health care.

So I didn’t do it here, but I’ve done it plenty of other places. And I have a new book coming out on medicine and the market, the role of the market in health care. And once again, I take up the question. My main objection to the market is it doesn’t give a damn about the goals of medicine. That is part of its problem.

Anyway, I have done it.

CHAIRMAN KASS: I’m just struck by the asymmetry in the presentation.

DR. CALLAHAN: In this presentation, I agree.

CHAIRMAN KASS: In this presentation.

DR. CALLAHAN: There is an asymmetry, but that is just an oversight. I have played that one out a lot in —

CHAIRMAN KASS: Would you, therefore, be satisfied —

DR. CALLAHAN: But I can’t.

CHAIRMAN KASS: Would you be satisfied if one pursued these goals of medicine in a limited way but that the questions of affordability and equity and economy were not alleviated?

DR. CALLAHAN: Well, I think we have to do both. I mean, it seems to me that there is no point in pursuing goals if you can’t afford to pay for the consequences of the pursuit.

Then you have got to live in a — I mean, I think one of the early debates I got in was arguing with many physicians who found it absolutely offensive to talk about money in the value of life at all, basically saying, “Look, you can’t put a value on life. The very notion that you might not pursue certain things to take account of money is itself a corruption of proper thinking about medicine.”

Well, I think that is simply wrong. You have to do it because modern contemporary medicine is a very expensive proposition. You can’t ignore the cost of everything.

CHAIRMAN KASS: Let me give Michael the last comment. And then you can have the last word, Dan.

PROF. SANDEL: Well, first, I hope you realize what a heavy price I’ve paid for coming to your support, Dan. It’s cost me all of my friends here with the possible exception of Gil.

(Laughter.)

PROF. SANDEL: Contrary to what Leon suspects, what makes me sympathetic to your proposal, it’s not just or primarily your emphasis on social solidarity and a critique of markets and universal health care, all of which I agree with you on. What I like about it is that those things are connected to something that Gil emphasized, which is an underlying religious and/or moral conception, which you haven’t made all that explicit here. And I think that’s made things more difficult for you. But it is implicit in your account. So that’s one friendly suggestion.

The other is related. I wouldn’t cast this as an argument against progress. I would describe this as calling into question what counts as genuine medical progress in human terms.

And, as I understand what you have in mind — and this fits with Gil’s proposal that there is a kind of moral or religious understanding underlying this — that what you are proposing is that we can’t answer the question what counts as genuine medical progress without asking questions about the nature of the good life and normative conception of health. And we can’t sort those out without trespassing on some religious and substantive moral questions.

If you put it more explicitly in those terms, well, you might still lose some around the table, but you might tempt others.

DR. CALLAHAN: Let me just say one final word. I don’t think I’ve ever said I’m against progress per se. We will go forward. Human beings change and always change. The question is I absolutely agree, what is good progress and bad progress?
But by taking a political stance on it, we have already demystified it a little bit. That's all.

**PROF. GEORGE:** Leon, if I could say just a very quick — it's probably just a very quick word because I want to say something about Dan's work in light of some of Paul's criticism.

I've been reading Dan's work for the 20 years I've been in the academic business. It's filled with proposals. Some of them I've agreed with. Some I've disagreed with.

I certainly commend Dan for making proposals, instead of doing the kind of philosophy that there is too much of that doesn't actually have a bottom line.

But I do want to say, even where I have disagreed, another one of the things about Dan's work is it aims to put forward the proposals to the public for democratic deliberation.

It's not, Paul, a question of elitism or imposing an expert's opinion from on high. The proposals in Dan's work are proposals for us to deliberate about and decide as a democratically constituted people whether we're going to go down this path or not.

**DR. MCHUGH:** I've also read Dan's work for a long time. And I agree that he is a Democrat and an American and he believes in all of those things. He even wants to quote, after all, polls. So that is a good thing.

I just think that behind it, behind these things, rests a presumption that somebody knows better than the average guy what he wants. And if that were turned loose in other directions, like Gil said, we wouldn't have iPods because we don't need them. We wouldn't have certain courses because we don't need them.

And it is embedded in there in the same way — and to some extent, the great thing about the Webbs and the Fabians is that they did have a moral persuasion. They just lost sight of their ultimate direction.

**CHAIRMAN KASS:** I think we should call this one. Those who are meeting for dinner, it's Bobby Van's restaurant. I think it's 806 15th Street, a couple of blocks from here, at 6:30, tomorrow morning 8:30. And we will be discussing the Council draft White Paper on alternative sources of stem cells and then a session on chimeras.

*(Whereupon, at 5:37 p.m., the foregoing matter was recessed, to reconvene at 8:30 a.m. on Friday, March 4, 2005.)*
Leon R. Kass, M.D., Ph.D., is the Addie Clark Harding Professor in the Committee on Social Thought and the College at the University of Chicago and Hertog Fellow in Social Thought at the American Enterprise Institute. He was chairman of the President’s Council on Bioethics from 2001 to 2005.

A native of Chicago, Dr. Kass was educated at the University of Chicago where he earned his B.S. and M.D. degrees (1958; 1962) and at Harvard where he took a Ph.D. in biochemistry (1967). Afterwards, he did research in molecular biology at the National Institutes of Health, while serving in the United States Public Health Service.

Shifting directions from doing science to thinking about its human meaning, he has been engaged for more than 30 years with ethical and philosophical issues raised by biomedical advance, and, more recently, with broader moral and cultural issues. From 1970-72, Dr. Kass served as Executive Secretary of the Committee on the Life Sciences and Social Policy of the National Research Council/National Academy of Sciences, whose report, Assessing Biomedical Technologies, provided one of the first overviews of the emerging moral and social questions posed by biomedical advance.

He taught at St. John’s College, Annapolis, MD, and served as Joseph P. Kennedy, Sr., Research Professor in Bioethics at the Kennedy Institute of Ethics at Georgetown University, before returning in 1976 to the University of Chicago, where he has been an award-winning teacher deeply involved in undergraduate education and committed to the study of classic texts.


His widely reprinted essays in biomedical ethics have dealt with issues raised by in vitro fertilization, cloning, genetic screening and genetic technology, organ transplantation, aging research, euthanasia and assisted suicide, and the moral nature of the medical profession.

Dr. Kass is married to Amy Apfel Kass, Senior Lecturer in the Humanities at the University of Chicago and Senior Fellow at the Hudson Institute. The Kasses have two married daughters and four young granddaughters.
BENJAMIN S. CARSON SR., M.D.

COUNCIL MEMBER

Benjamin Solomon Carson Sr. is the Director of Pediatric Neurosurgery at the Johns Hopkins Medical Institutions, a position he has held since 1984. He is a professor of neurosurgery, oncology, plastic surgery, and pediatrics.

In 1987, he gained world-wide recognition as the principal surgeon in the 22-hour separation of the Binder Siamese twins from Germany. This was the first time occipital craniopagus twins had been separated with both surviving. In 1997, Dr. Carson was the primary surgeon in the team of South African and Zambian surgeons who separated type-2 vertical craniopagus twins (joined at the top of the head) in a 28-hour operation. It represents the first time such complexly joined Siamese twins have been separated with both remaining neurologically normal.

He is noted for his use of cerebral hemispherectomy to control intractable seizures as well as for his work in craniofacial reconstructive surgery, achondroplasia (human dwarfism), and pediatric neuro-oncology (brain tumors).

Dr. Carson is a recipient of numerous honors and awards including more than 20 honorary doctorate degrees. He is a member of the American Academy of Achievement, the Horatio Alger Society of Distinguished Americans, the Alpha Omega Alpha Honor Medical Society, and many other prestigious organizations. He sits on many boards including the Board of Directors of Kellogg Company, Costco Wholesale Corporation, Yale Corporation (the governing body of Yale University), and America’s Promise.

He is the president and co-founder of the Carson Scholars Fund which recognizes young people of all backgrounds for exceptional academic and humanitarian accomplishments.

He is the author of *Gifted Hands*, *THINK BIG*, and *The Big Picture*.

Dr. Carson has been married to Candy Carson for twenty-five years and has three sons.

<< previous :: Return to Council Member List :: next >>
REBECCA DRESSER, J.D., M.S.

COUNCIL MEMBER


<< previous :: Return to Council Member List :: next >>
DANIEL FOSTER, M.D.

COUNCIL MEMBER

Daniel Foster, M.D. John Denis McGarry, Ph.D. Distinguished Chair in Diabetes and Metabolic Research, University of Texas Southwestern Medical School. Dr. Foster, whose research is in intermediary metabolism, has received the Banting Medal, the Joslin Medal, the Tinsley R. Harrison Medal and the Robert H. Williams Distinguished Chair of Medicine Award for his work. He is a member of the Institute of Medicine of the National Academy of Sciences and is a Fellow of the American Academy of Arts and Sciences. He was chairman of the Department of Internal Medicine at UT Southwestern for 16 years.

<< previous :: Return to Council Member List :: next >>
FRANCIS FUKUYAMA, PH.D.

COUNCIL MEMBER

Francis Fukuyama is Bernard L. Schwartz Professor of International Political Economy at the Paul H. Nitze School of Advanced International Studies of Johns Hopkins University.

Dr. Fukuyama’s book, *The End of History and the Last Man*, was published by Free Press in 1992 and has appeared in more than twenty foreign editions. It made the bestseller lists in the United States, France, Japan, and Chile, and has been awarded the *Los Angeles Times’* Book Critics Award in the Current Interest category, as well as the Premio Capri for the Italian edition. He is also the author of *Trust: The Social Virtues and the Creation of Prosperity* (1995); *The Great Disruption: Human Nature and the Reconstitution of Social Order* (1999); and *Our Posthuman Future: Consequences of the Biotechnology Revolution* (2002). His most recent book, *State-Building: Governance and World Order in the 21st Century*, was published by Cornell University Press in the spring of 2004.

Dr. Fukuyama has written widely on issues relating to questions concerning democratization and international political economy. He has, in recent years, focused on the role of culture and social capital in modern economic life, and on the social consequences of technological change.

Francis Fukuyama was born in Chicago on October 27, 1952. He received his B.A. from Cornell University in classics, and his Ph.D. in political science from Harvard. He was a member of the Political Science Department of the RAND Corporation from 1979-1980, then again from 1983-89, and from 1995-96. In 1981-82 and in 1989, he was a member of the Policy Planning Staff of the US Department of State, the first time as a regular member specializing in Middle East affairs, and then as Deputy Director for European political-military affairs. In 1981-82 he was also a member of the US delegation to the Egyptian-Israeli talks on Palestinian autonomy. From 1996-2000 he was Omer L. and Nancy Hirst Professor of Public Policy at the School of Public Policy at George Mason University.

Dr. Fukuyama is a member of the President’s Council on Bioethics. He holds an honorary doctorate from Connecticut College and Doane College, and is a member of advisory boards for the National Endowment for Democracy (NED), *The National Interest*, the *Journal of Democracy*, and The New America Foundation. As an NED board member, he is responsible for oversight of the Endowment’s Middle East programs. He is a member of the American Political Science Association, the Council on Foreign Relations, the Pacific Council on International Policy, and the Global Business Network. He is married to Laura Holmgren and has three children.
ROBERT P. GEORGE, J.D, D.PHIL.

COUNCIL MEMBER

Robert P. George is McCormick Professor of Jurisprudence and Director of the James Madison Program in American Ideals and Institutions at Princeton University.


In 2008, Professor George received the Presidential Citizens Medal at a ceremony in the Oval Office of the White House. He is a winner the Bradley Prize for Intellectual and Civic Achievement; the Sidney Hook Memorial Award of the National Association of Scholars; and the Philip Merrill Award for Outstanding Contributions to the Liberal Arts of the American Council of Trustees and Alumni.

A graduate of Swarthmore College and Harvard Law School, Professor George earned a doctorate in philosophy of law from Oxford University. He was elected to Phi Beta Kappa at Swarthmore, and received a Knox Fellowship from Harvard for graduate study in law and philosophy at Oxford. He holds honorary doctorates of law, letters, science, ethics, civil law, humane letters, and juridical science.

Professor George is a member of UNESCO’s World Commission on the Ethics of Scientific Knowledge and Technology. From 1993-98, he served as a presidential appointee to the United States Commission on Civil Rights. He is also a former Judicial Fellow at the Supreme Court of the United States, where he received the 1990 Justice Tom C. Clark Award. He is the recipient of a Silver Gavel Award of the American Bar Association, the Paul Bator Award of the Federalist Society for Law and Public Policy. In 2007 he gave the John Dewey Lecture in Philosophy of Law at Harvard. In 2008 he gave the Judge Guido Calabresi Lecture at Yale and the Sir Malcolm Knox Lecture at the University of St. Andrews in Scotland.

Professor George is a member of the Council on Foreign Relations, and serves as Of Counsel to the law firm of Robinson & McElwee.
**Alfonso Gómez-Lobo, Dr. phil.**

**Council Member**

Alfonso Gómez-Lobo, Dr. phil. Ryan Family Professor of Metaphysics and Moral Philosophy, Georgetown University. Professor Gómez-Lobo specializes in Greek philosophy, Greek historiography, the history of ethics, and contemporary natural law theory. He is the recipient of several awards, including a research fellowship from the Guggenheim Foundation. His latest book, *Morality and the Human Goods*, was published by Georgetown University Press in 2002.
WILLIAM B. HURLBUT, M.D.

COUNCIL MEMBER

William B. Hurlbut, M.D. Consulting Professor, Department of Neurology and Neurological Sciences, Stanford Medical Center, Stanford University. Dr. Hurlbut's main areas of interest involve the ethical issues associated with advancing biotechnology and neuroscience, the evolutionary origins of spiritual and moral awareness, and the integration of philosophy of biology with theology. He has worked with the Center for International Security and Cooperation on a project formulating policy on Chemical and Biological Warfare and with NASA on projects in astrobiology. He is the author of "Altered Nuclear Transfer," a technological proposal to our nation's impasse over stem cell research.

<< previous :: Return to Council Member List :: next >>
CHARLES KRAUTHAMMER, M.D.

COUNCIL MEMBER

Charles Krauthammer, M.D., Syndicated columnist. Dr. Krauthammer, a board-certified psychiatrist who received his medical degree from Harvard Medical School and practiced psychiatry at Massachusetts General Hospital for several years, writes a nationally syndicated editorial page column for The Washington Post Writers Group. He won the 1987 Pulitzer Prize for distinguished commentary. For 20 years, he has written articles on several bioethical topics, including human experimentation, stem cell research, cloning, euthanasia, and assisted suicide.

Dr. Krauthammer was a recipient of the Inaugural (2003) Bradley Prize, awarded by the Lynde and Harry Bradley Foundation, as well as the recipient of the 2004 Irving Kristol Award, given by the American Enterprise Institute.
PETER A. LAWLER, PH.D.

COUNCIL MEMBER

Peter Augustine Lawler is Dana Professor and Chair of the Department of Government and International Studies at Berry College. He teaches courses in political philosophy and American politics and has won several awards from Berry for doing so.

He is executive editor of the acclaimed quarterly journal, *Perspectives on Political Science*, and has been chair of the politics and literature section of the American Political Science Association. He also serves on the editorial board of the new bilingual critical edition of Alexis de Tocqueville’s *Democracy in America* and on the editorial boards of several journals. He is a member of the Society of Scholars at the Madison Center at Princeton University, the George Washington Professor on the American founding for the Society of Cincinnati for the state of Georgia, and he is a member of President Bush’s Council on Bioethics.

He has written or edited ten books. His newest book, *Aliens in America: The Strange Truth about Our Souls* is a starred, featured selection in *Booklist*, the journal of the American Library Association. Another recent book, *Postmodernism Rightly Understood*, was also widely reviewed and praised. His very long introduction to a new edition of Orestes Brownson’s *The American Republic* is now available.

His *American Political Rhetoric* (edited with Robert Schaefer) is used in introductory American government courses at a sizeable number of colleges and universities. The fifth edition was just published.


Some of the topics of his recent articles and chapters include Shakespeare’s *The Tempest*, William Alexander Percy, Walker Percy, Alexis de Tocqueville, biotechnology, bourgeois bohemian virtue, religion and conservatism, compassionate conservatism, conservationism, the filmmaker Whit Stillman on nature and grace, disco and democracy, *Casablanca* and the American dream, the future of human nature, the utopian eugenics of our time, the rise and fall of sociobiology, Richard Rorty, grade inflation and the Ivy League, Harvey Mansfield and Carey McWilliams, caregiving and the American individual, Christopher Lasch, virtue voters, culture wars, Flannery O’Connor and nihilism, Orestes Brownson, and postmodernism rightly understood.

Lawler has given invited lectures at more than 50 colleges and universities. He has received a large number of grants from both the Liberty Fund and the Earhart Foundation, as well as numerous other foundations.

Dr. Lawler recently edited a book on Tocqueville and American political life today and the fifth edition of *American Political Rhetoric.* He wrote an introduction to the new Sheed and Ward edition of John Courtney Murray’s *We Hold These Truths*, and book chapters on religion and the American founding, Locke and American greatness, Flannery O’Connor, and *Casablanca.*
Paul McHugh, M.D.

Council Member

Paul R. McHugh, M.D. is the University Distinguished Service Professor of Psychiatry at the Johns Hopkins University School of Medicine. He was the Henry Phipps Professor of Psychiatry, Director of the Department of Psychiatry and Behavioral Sciences at the Johns Hopkins University School of Medicine, and psychiatrist-in-chief at the Johns Hopkins Hospital from 1975-2001. He is the author of 4 books and more than 150 papers.

<< previous :: Return to Council Member List :: next >>

The President's Council on Bioethics

Home Site Map Disclaimers Privacy Notice Accessibility NBAC HHS
GILBERT MEILAENDER, PH.D.

COUNCIL MEMBER

Gilbert Meilaender, Ph.D. Richard & Phyllis Duesenberg Professor of Christian Ethics at Valparaiso University. Professor Meilaender is an associate editor for the Journal of Religious Ethics. He has taken a special interest in bioethics and is a Fellow of the Hastings Center. His books include Bioethics: A Primer for Christians (1996, 2005), Body, Soul, and Bioethics (1995). He has recently edited (together with William Werpehowski) The Oxford Handbook of Theological Ethics.

<< previous :: Return to Council Member List :: next >>
JANET D. ROWLEY, M.D., D.Sc.

COUNCIL MEMBER

Janet D. Rowley, M.D., D.Sc. Blum-Riese Distinguished Service Professor of Medicine, Molecular Genetics and Cell Biology, and Human Genetics, Pritzker School of Medicine, University of Chicago. Dr. Rowley is internationally renowned for her studies of chromosome abnormalities in human leukemia and lymphoma. She is the recipient of the National Medal of Science (1999) and the Albert Lasker Clinical Medicine Research Prize (1998), the most distinguished American honor for clinical medical research.

<< previous :: Return to Council Member List :: next >>

The President's Council on Bioethics

Home Site Map Disclaimers Privacy Notice Accessibility NBAC HHS
MICHAEL J. SANDEL, D.PHIL.

COUNCIL MEMBER

Michael J. Sandel, D.Phil., Professor of Government, Harvard University. Professor Sandel, who was a Rhodes Scholar, teaches contemporary political philosophy and the history of political thought. Sandel's books include *Democracy's Discontent: America In Search of a Public Philosophy* (1996) and * Liberalism and the Limits of Justice* (1982). He has received fellowships from the Ford Foundation, the American Council of Learned Societies, and the National Endowment for the Humanities.

<< previous :: Return to Council Member List :: next >>
DIANA J. SCHAUB, PH.D.

COUNCIL MEMBER

Diana J. Schaub is a professor and chairwoman of the department of political science at Loyola College in Maryland. From 1994 to 1995 she was the postdoctoral fellow of the Program on Constitutional Government at Harvard University. In 2001, she was the recipient of the Richard M. Weaver Prize for Scholarly Letters. Ms. Schaub has taught at the University of Michigan at Dearborn and served as assistant editor of the National Interest. She has her A.B. from Kenyon College, where she was elected to Phi Beta Kappa, and an M.A. and Ph.D. from the University of Chicago. She is the author of Erotic Liberalism: Women and Revolution in Montesquieu's "Persian Letters" (1995), along with a number of book chapters and articles in the fields of political philosophy and American political thought. Ms. Schaub's work also appears in the New Criterion, the Public Interest, and The American Enterprise.
James Q. Wilson, Ph.D.

COUNCIL MEMBER

James Q. Wilson, Ph.D. The James A. Collins Professor of Management and Public Policy Emeritus at the University of California Los Angeles and a lecturer at Pepperdine University. Professor Wilson, one of the nation’s most respected political scientists, has written extensively on human nature and ethics. His publications include *The Moral Sense* (1997) and *Moral Judgment: Does the Abuse Excuse Threaten Our Legal System?* (1998). He has received numerous awards and honors, including the Presidential Medal of Freedom.