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### Title

Deadly Disputes: The Body in Death in Japan, North America, and Europe

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DEADLY DISPUTES

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MARGARET LOCK

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STEPHEN JAMISON

CHARLES LESLIE

GUY MICCO



# Deadly Disputes

Understanding Death in Europe,  
Japan, and North America



THE DOREEN B. TOWNSEND CENTER FOR THE HUMANITIES was established at the University of California at Berkeley in 1987 in order to promote interdisciplinary studies in the humanities. Endowed by Doreen B. Townsend, the Center awards fellowships to advanced graduate students and untenured faculty on the Berkeley campus, and supports interdisciplinary working groups, discussion groups, and team-taught graduate seminars. It also sponsors symposia and conferences which strengthen research and teaching in the humanities and related social science fields. The Center is directed by Thomas W. Laqueur, Professor of History. Christina M. Gillis has been Associate Director of the Townsend Center since 1988.

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DEADLY DISPUTES contains the proceedings of two symposia held in April of 1995 on the UC Berkeley Campus. On April 18, Professor Margaret Lock presented "Deadly Disputes: Biotechnology and Reconceptualizing the Body in Death in Japan and North America," and on April 20, Professor Alexander Capron presented "Legalizing Physician-Assisted Death: A Skeptic's View." Both talks were part of the Townsend Center's PROJECT ON DEATH AND DYING IN AMERICA, and were generously supported by the Academic Geriatric Resource Program. The project is part of an ongoing Townsend Center initiative on HUMANITIES AND PUBLIC VALUES, which encourages interdisciplinary dialogue in those areas of human concern where the Humanities can make meaningful contributions.

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## INTRODUCTION

Several weeks ago a local journalist called to ask why there was so much interest in aging, death, and dying in “unusual” places like the humanities. Why, he wondered, was a humanities center taking up questions like these.

The short answer is that death and dying, like living and loving, are preeminently subjects of concern for humanistic thinking and have been for many generations. As to why the interest now, we could no doubt marshal a number of demographic and economic answers; but these would be inadequate without an account of historical and cultural factors. This is a crucial point in the Townsend Center’s programs on aging, death and dying.

The Center’s aim in Occasional Paper No. 4 is to locate those areas where the Humanities can connect with and contribute to issues with broad social import, either through the generation of new scholarship or the facilitation of multidisciplinary conversations among academics and professionals in other domains, particularly Law and Medicine. Our purpose in the project as a whole is to broaden the range of practices and practitioners engaged with far-reaching questions common to many disciplines. It will be no news to people in this audience that the deep human experience of dying and of making decisions about dying cannot be understood simply as a technical problem. Similarly, not only a biological transition, the experience of death is both culturally constructed and historically contingent.

Anthropologist Margaret Lock offers us in her talk, “Deadly Disputes,” a comparative analysis of attitudes toward the body in death in Japan and North America and how these dual perspectives inform cultural attitudes toward organ transplant in the two cultures. Legal scholar Alexander Capron turns, in “Legalizing Physician-Assisted Death,” to what he calls the “skeptic’s view,” examining policy implications—what he calls “practical matters”—as well as the more difficult question of what we mean by a patient’s “right to die.”

The Townsend Center was delighted to welcome Alexander Capron and Margaret Lock, along with commentators and chair Lawrence Cohen, Stephen Jamison, Charles Leslie, and Guy Micco to these symposia. We also deeply appreciate the support of the Academic Geriatric Resource Center in making these programs possible.

CHRISTINA GILLIS  
Associate Director  
Doreen B. Townsend  
Center for the Humanities



# Contents

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## Deadly Disputes

Lawrence Cohen	3
Margaret Lock	7
Commentary	
Charles Leslie	27
Guy Micco	30

## Legalizing Physician-Assisted Death

Alexander Capron	38
Commentary	
Stephen Jamison	52

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# **Deadly Disputes**

**Biotechnology and Reconceptualizing**

**the Body in Death In Japan**

**and North America**

**Margaret Lock**

with commentary by

Professor Charles Leslie

and

Doctor Guy Micco



## Introductory Comments by Lawrence Cohen

It's a pleasure to share this afternoon's discussion and to introduce Dr. Margaret Lock, an anthropologist and Professor at McGill University in Montreal. Her talk today is called "Deadly Disputes: Biotechnology and Reconceptualizing the Body in Death in Japan and North America." It is a rich talk and it will engage issues ranging from organ transplant technologies, brain death and other new forms of death, medicine, doctors, culture and debates on culture in Japan, aging, dying and the body, and what all these things might have to do with the global culture in which technologies, ethics, meanings, bodies and deaths can be exported and reproduced in interesting new ways.

I promised Professor Lock that I would attempt to tie in death in Japan with my own origins as an anthropologist of South Asia. To briefly deliver an embarrassing story. . . When I was a freshman in college, a biology student, like Professor Lock, who started out as a biochemist, I wanted to take a course that wasn't a science course. I applied to a freshman seminar about Japan. The only reason I had an interest in Japan was because my grandfather had passed away in Japan while on business there. My family was away and I was on the phone as a high school student trying to bring the body back. I encountered many problems, which I, at the time, termed "cultural," in trying to get Grandpa's body back. When I tried to get into this seminar on Japan, the professor asked me—since this was an elite East-Coast university and you had to apply to get into seminars—"Well, why, young man, are you interested in Japan?" I thought it was in rather poor taste to mention, as I am doing now, the story of getting my grandfather's body shipped back home, but I had nothing else to offer, so I said, "Well, I've read *Shogun*." And I didn't get in. I study India as a consequence. And that's a true story.

There are other links, though, and I want to draw a more serious one. Thomas Mann wrote a legend of India, which he called “The Transposed Heads.” It is a story of two best friends who fall in love with the same woman, and who recognize their murderous impulses towards each other because of their jealousy. They commit suicide each in turn, in a rather Orientalist way; but not of that here. The goddess Kali, to whom they dedicate their deaths, speaks afterwards to the poor woman, who survives her two lovers, and tells her to replace the heads but do it quickly, and thus resuscitate the corpses. But in her haste, the girl reverses the heads, leading to an early, if mythic, example of head transplant surgery.

This is not just a joke. When the great Hindu epic, *The Mahabharata* was recently televised in India, one episode caused some excitement. Krishna’s mother is pregnant with her son, Ballarama, who is born before Krishna, and they are imprisoned by an evil king who is going to destroy all products of this marriage. The child is saved through various magical means, transporting the fetus from the mother to another woman. When this episode aired, it was spoken about in the media as the first example of transplant surgery, and it was done in ancient India. The politics behind the appropriation are, of course, interesting, and they are politics to which the work of Professor Leslie has alerted us for several years. Notwithstanding the appropriation of mythic transports of fetuses from one body to another, the question of organ transplants in South Asia is a big one, and it ties up in interesting ways with the debate here between Japan and North America. For our future discussion, I’d like to insert this point: in much of the world, people are selling their organs. Organs are being bought and sold on the international market. This traffic has reached large proportions, both in rumors of kidnappings and unwilling organ sales, which affect international politics, and also in the very real sale of organs. That market has increased. I got a letter recently from a friend who was planning to sell his kidney to pay his sister’s dowry. This happens quite a lot, and it’s rather serious. As rumors of HIV infection increasing in the population reach buyer nations in Asia and the Middle East, buyers are beginning to worry that these might be tainted goods. These are very real issues.

Thus, I turn you to a talk called “Deadly Disputes,” and these are deadly indeed. First, however, I’d like to introduce our discussants and our main speaker. Professor Charles Leslie is a visiting professor of medical anthropology here in the Anthro-

pology Department. He is famous for many things, one of which is that he has really led the way in what he calls Medical Revivalism, the ways in which traditional medicine takes on very new forms as part of nationalist science. The other area of work in which he has distinguished himself is in having edited two volumes that have transformed the field both of anthropology generally and medical anthropology in particular: *Asian Medical Systems* and with Alan Young, and *A Path Towards Asian Medical Knowledge*. Our second speaker, Guy Micco, does many things. He is a physician and internist at Alta Bates Hospital. He's one of the main figures who makes the joint medical program between Berkeley and UCSF work. He runs the ethics committee at Alta Bates Hospital and therefore is a practicing ethicist. He has his influence in our own Academic Geriatric Resource Program and elsewhere. He is also an Associate Clinical Professor both here and at UCSF, but most importantly, he is the advice-giving physician for almost the whole UC Berkeley faculty. Whenever anyone has a medical problem, they call Guy Micco. He brings all of these perspectives to our talk today.

Professor Margaret Lock went West at one point in her life. She went all the way from Europe to California, where she ended up a scientist, had a major life change and became an anthropologist here at Berkeley and UCSF. She produced, in 1976, her dissertation, *East Asian Medicine in Urban Japan: A Harmony of Tradition and Science*. She is thus very much a homegrown product, and we are very fortunate to have her back today. She went on to write and also edit several very important books. *East Asian Medicine in Urban Japan: Varieties of Medical Experience* really articulated first in North America the study of traditional Japanese medicine in a very new way. The care and attention to various forms of data and data collection characterizes Professor Lock's work, especially in her most recent work, *Encounters With Aging: Mythologies of Menopause in Japan and North America*. This book brings together, in a very interesting way, quantitative and qualitative material in the study of aging. It brings together work on Japan and work on North America. It brings together anthropology and history, and does this with a variety of frameworks and a variety of field methods. It's a tremendously important work not only for studying Japan, women's studies, and menopause, but also for the whole field of aging. She has edited many volumes. I'll mention the two most recent because they've really transformed medical anthropology. One of them is called *Biomedicine Examined*,

and the other is *Knowledge, Power and Practice: The Anthropology of Medicine and Everyday Life*, both of which she co-edited. She has been one of the major anthropologists who has brought together a lot of questions in the anthropology of medicine, science and science studies in North America.

**Margaret Lock**

**Deadly Disputes**

One vivid memory I retain from the Second World War of being wheeled on a gurney into hospital after our family house was destroyed by a rocket which had fallen short of its London target, is of an iron lung standing massive and scary outside the ward where I was placed. The iron lung was used, we kids all knew, for severe cases of polio, which was the infectious disease causing the greatest havoc among our lives at the time. Tales circulated amongst us as we traded our shrapnel collections about the iron lung and who had died encased inside it. Together with the nightly air raids, this contraption signaled that death lurked close by. We made sick jokes about the technologies of both war and medicine to hide our terror. *The Iron Lung*

What I want to talk about today reflects part of my current interest in the way in which conceptualizations about and definitions of life and death, normality and pathology are contested and reconstructed in association with the development of new biomedical technologies. And simultaneously I am concerned with the relationship among politics, scientific knowledge production and its application, and the creation of so-called “needs” among populations, together with the search for moral order and control in contemporary society. A lot of these themes will be *implicit* in the talk I will be giving today, although some of them will be much more obvious. I hope that in the discussion some of them will come out in a way that we’ll take up later and debate.

I will begin by tracing the train of events that was set in motion by the creation of this contraption—of the iron lung—in Denmark in the 1950s and what has happened since that time. First of all, I want to introduce you briefly to my theoretical perspective, without turning the talk entirely into a deep theoretical discussion. The history of technology, at least in the West, has usually been transmitted as an heroic tale about the conquest of the enemy, whether it be human or the natural world, a narrative of progress and of the betterment of humanity in *Theoretical Considerations*

general. Of course its dominant ideology has, for the past one hundred years at least, been accompanied by a counter-discourse about the consequences about technology gone wild. From Mary Wollstonecraft Shelly to Charles Dickens, and on to Kurt Vonnegut, Jr. and many others, we read in novels of the havoc and the misery which technology can create.

The Humanities and the Social Sciences have also sounded regular warnings. Jacques Ellul, for example, stated that “technique has become autonomous. It has fashioned an omnivorous word which obeys its own laws and which has renounced all tradition.” This is a sentiment which has been echoed by John Kenneth Galbraith, René DuBos, Martin Heidegger, and by many other people all from their different vantage points. Autonomy in the Kantian tradition is of course associated with the notion of free will, of an individual no longer subject to externally created laws and, as Langdon Winner has pointed out, “the very idea of an autonomous technology raises an unsettling irony for the expected relationship of subject and object is exactly reversed.” We humans have apparently lost out to the monster, but nevertheless rush eagerly ahead creating new devices. Like Shiva in Hindu iconography, Bryan Pfaffenberger has suggested, technology as seen through a modernist lens at least, is both creator and destroyer, an agent of future promise and of culture’s destruction.

It has generally been assumed that the major driving force behind the creation of technologies is to meet universal human needs. Marcuse and Habermas, for example, believed that the creation of technology is a rational endeavor and expressly carried out to meet human needs, and therefore for them there is nothing inherently questionable about the production of technology or its application, provided that one goes about it in an equitable way such that the interests of powerful élites are not simply masked in implementing the technology. But anthropologists have taken a rather different approach.

Both George Basalla and Marshall Sahlins have taken more radical positions, and I think these are positions many anthropologists would agree with. They stress that aside from the fundamental requisites for sustaining life, it is culture and not nature which defines necessity. Necessity is not, after all, the mother of invention



in any predetermined way. On the contrary, human technology is a material manifestation of the various ways men and women throughout time have chosen to define and pursue existence. Technology is thus an integral part of the history of human aspirations and, to paraphrase Basalla, the plethora of made things are a product of human minds replete with fantasies, longings, wants and desires. Simply to link technology with power is to leave tacit the dominant modernist ideology of progress as an inherently rational pursuit to which culture makes no contribution.

It is easy to assume that among the many forms of technology those related to medicine exist by definition to meet basic human needs, in particular to reduce suffering and avert premature death. It's not surprising perhaps that aside from a concern about runaway expenditure and unwanted side-effects on the body, there's been, until recently, relatively little resistance in principle to the development and application of medical technology. An assumption usually holds sway that techniques that allow us to penetrate with increasing efficiency into the recesses of the body, together with those that supposedly relieve pain and prolong life, are inevitably for the good.

But I assume all of us in this room, at least, realize by now that biomedical technologies are by no means autonomous, and moreover that the characterization of suffering and needs, being culturally constructed, has a profound influence on the development, associated discourse, and application of these technologies. It is in connection particularly with the application of reproductive technologies, neonatal intensive care, genetic engineering, organ transplantation, and dying, that contested domains have become most evident. That dispute has emerged around these dramatic manipulations should come as no surprise, for their application necessarily involves debate about tacit knowledge as to what constitutes life and what constitutes death.

Were it not for the development of first the iron lung, an ostensibly autonomous, supremely utilitarian piece of technology, followed in the late 1950s by its successor, the artificial respirator or ventilator, by means of which many people who can no longer breathe independently are kept alive, there would be no debate today about the reduction of suffering and the saving of lives through transplant

technology. The artificial respirator clearly meets a basic need, but the uses to which it's put today have far-reaching implications beyond the simple function of sustaining breathing on a temporary basis. Once the existence of patients on the artificial ventilator was harnessed to the heroic and showy technology of major transplants, it became apparent to those involved in the medical world that there was an urgent need to clarify what exactly is meant by biological death. And it would seem, of course that there's very little room for ideological posturing in connection with death. Most of us raised in contemporary Euro-America believe, I suspect, that death is a rather easily-definable point of no return about which there's little argument.

*Japan and  
North America*

Japan, like North America, is in theory a predominantly secular society and similarly driven by principles of rational order and scientific progress—principles which are evident in many aspects of the health care systems on both sides of the Pacific. However, in Japan, the possibility of tinkering with death has opened up the floodgates of a concern which reaches way beyond the demise of individuals.

In North America, death was quietly redefined in 1968 by an élite group composed almost entirely of Harvard physicians, so that brain death could be accepted as the end of human life together with the then-current definition: cessation of heartbeat and respiration, a definition of death that we did not abandon. One could define death either with the older terms, or with the new definition of “brain death.” This was modified somewhat in 1981 so that the concept of whole-brain death is now recognized in the Uniform Determination of Death Act as the end of life. There was a brief period in the late 1960s when public concern about these changes was evident but today, in the great majority of North American hospitals, the concept of brain death is accepted as the end of life, and the harvesting of organs from brain-dead bodies has become routinized. Japan, on the other hand, has never accepted this concept of brain death, and therefore they cannot do major transplants; they are not able to do heart, liver and lung transplants using brain dead donors at all.

This contrast between North America and Japan invites comparison of the different forms the search takes in late modernity for the relief of suffering and the

creation of a just and moral order, together with an examination of the relationship this search has to the production and application of scientific and technological knowledge.

I'm going to switch now to the Japanese end of the story.

The highly stylized Japanese dramatical form known as Noh has been a forum since the 14th century for an exploration of the relationship between the world of spirits and earthly life. A conservative tradition to say the least, it's very rare indeed for anything written later than the mid-19th century to enter the consecrated canon which is actually performed in public. However, in 1991 a play entitled *The Well of Ignorance*, the creation of an eminent Tokyo immunologist, Tomio Tada, was premiered at the National Noh Theater to a standing-room-only crowd. The play is about a fisherman knocked unconscious in a storm and taken for dead. The wealthy father of a young woman who is very ill summons a Chinese doctor who removes the fisherman's heart and uses it to save the woman's life. The ensuing drama focuses both on the plight of the donor of the heart, who remained hovering in the world of restless spirits, neither alive nor dead, and the guilt which wracks the young woman for having caused such misery. The narrative in Noh, as many of you know, is furnished by a chorus of chanters accompanied by traditional musical instruments. It's through them that the fisherman describes the removal of his own heart.

*The Well of  
Ignorance*

When I was barely holding on to life, the doctors decided to come at me with blades and scissors. They opened my chest and took my beating heart out. And I heard the sounds of snipping and cutting, but my body was totally frozen, and no voice came out when I screamed, "Am I living, or am I dead?"

In characteristic Japanese form, the ambiguity is unresolved by end of the play. The spirit remains suspended and mutilated, and the young woman's efforts to purify herself at the village well prove fruitless because the well dries up, according to the villagers, by a curse.

Dr. Tada, in private conversation, claims that he personally has no objection to organ transplants, but I find this rather difficult to believe. He has a lifelong interest in Noh, but despite this he had to overcome a great deal of inertia to get this play

performed. I think he deliberately chose the medium of Noh to portray one of the most, perhaps *the* most controversial biomedical and bioethical issue in Japan today. In choosing the medium of Noh and not the contemporary theater, Dr. Tada was able to give the drama mythological dimensions, to infuse it with mystical and nostalgic associations. Although the play can be read simply as an allegory for the current national debate in Japan about the acceptability or otherwise of brain death, at the same time, I think, particularly because Dr. Tada is using Noh, it represents much more than this. For it's designed to unify the audience subtly by drawing on and rekindling their sensitivity to the unique qualities widely attributed to being Japanese, including shared attributes about the relationship of the natural, cosmological, and cultural domains. Dr. Tada agrees with this when one asks him. He says, "Yes, I really wanted we Japanese to think about this issue."

As I've indicated, there are some remarkable differences at the present time between Japan and North America with respect to organ transplants. For example, whereas in the United States there were nearly two thousand heart transplants in 1990, in Japan, there were none. No one needs to be told that this difference is not due to the lack of technology or skills, or to a shortage of economic resources on the part of the Japanese. So cultural differences must be at work, we assume. The tendency at the outset, or my tendency at least, was to ask what it is about Japanese and *not* North American culture which could account for this discrepancy. What widely-shared knowledge do the Japanese possess which makes them resistant to the technologically aided extension of human life? This approach seems particularly pertinent because Japan makes greater use of, and exports more medical technology than any other country in the world. Is this cultural difference to be found at the level of attitudes towards the mastery of nature or, more specifically, to a concern about tinkering with the bodies of the dying and the dead? Is Japan perhaps not as secular, not as rational, not as modern as its outward trappings lead us to believe? Alternatively, is it perhaps due to cultural differences in the actual production of scientific discourse about death and dying in Japan? Or is the difference due largely to the way in which the power and interests of doctors are played out and the form of institutionalization that medicine takes in Japan? Or is it some combination of the above?

I can't give you final answers to this puzzle, but I can give some suggestions and ideas from some of the directions I've been taking as I explore this problem.

It's relatively easy to take off from this starting point, to embrace an implicit assumption that there's something inherently odd about not striving to save lives in a secular society with neither economic nor technological constraints, to set out, therefore, to scrutinize the relics of tradition, survivals from an archaic past lurking in Japanese late modernity, which account for this anomaly. But, such an approach does violation to the majority of interpretations given by the Japanese on the subject, many of whom flatly deny that culture—that is, the culture of tradition—is involved. They argue instead for a more pragmatic explanation to do with social organization in which politics and power relationships among the professions and between the medical world and the public are the most important factors. Equally important, by focusing upon Japan as the anomaly, North American and European assumptions about suffering and about the good and just society remain unproblematized, and thus implicitly the norm for the modern world, something that also concerns many participants in the brain death debate as it unfolds in Japan.

Having said that, and for reasons of time here today, I'm not going to focus much on the North American end of the issue, but will leave it quite implicit and hope it is taken up in the discussion afterwards.

Shortly after the world's first heart transplant was conducted in South Africa, a good number of attempts were made in other locations to carry out the same procedure; one of these was Sapporo, Hokkaido in 1968. As in other parts of the world, the Sapporo procedure initially produced an accolade from the media and was heralded as a dramatic medical triumph. Several months later, however, the physician in charge, Dr. Wada, was arraigned on a charge of murder and only acquitted after six years of fighting. The majority of Japanese in retrospect believe that the patient whose heart was removed was not brain dead, and that the recipient, who died two and a half months after the operation, was not sufficiently in need of a new heart to have undergone the procedure in the first place.

*History of the  
Controversy*

As part of the current national debate about organ transplants, discussion of the case was formally re-opened in 1991 and the chairman of the Japanese Medical

Association, testifying before a government committee, reported that twenty-three years previously, right after the removal of the supposedly ineffective heart from the recipient patient, it had been tampered with, indicating that the involved doctors may have tried to exaggerate the degree of its deterioration. The case is now considered by just about everybody in Japan as a barbarous piece of medical experimentation carried out by a doctor who, significantly, had received a good portion of his training in the United States. He also happens to come from Hokkaido, which is considered the frontier zone of Japan—it's like living in the old Wild West in a way—and he also happens to have a kind of personality which many Japanese feel is not really Japanese: he's very flamboyant and very outspoken, all of which place him in a very bad light. He is also the model for the Chinese doctor who appears in the Noh play that Tomio Tada produced; Dr. Tada is explicit that he is making a link between the current problems and his drama set in mythological times.

Again, I don't have the time to go into detail today, but if one goes back through the literature on the first heart transplants and reconsiders the case in South Africa very carefully, one will find that it is not so very different from this case in Japan. That's something we tend to forget about.

There have been other cases in connection with organ transplants where the Japanese medical profession hasn't shown up in a good light. One involved a highly controversial kidney and pancreas transplant at a major university in which organs were removed from a young mentally retarded woman. She had been diagnosed as brain dead, but neither she nor her parents had given permission for any organs to be removed. There have been ten or twelve other major examples of this kind in Japan, which has not led the public to feel calm about debates over the redefinition of death and the question of transplants.

It is illegal to buy and sell human organs in Japan, but since there has been a long-standing custom of giving substantial gifts to doctors to ensure good medical care—especially in the case of surgeons—a practice a few people describe as bribery, many Japanese believe that the commodification of human organs is a realistic possibility, and may already be in operation. Recently, one out of work man advertised in a Japanese newspaper to sell his kidney for about \$5,000, which

actually is not very much money for a kidney. In contrast to India, that kind of advertisement is thought of as really outrageous in Japan, and the response was very negative.

I would like to fill in the background a little bit more, because the Japanese experience is so different from that which we have had in North America. For example, recently in the past couple of years, in full view of the nation as it watched on television, police entered Osaka University Hospital to issue a warning to surgeons that they shouldn't remove the liver of a patient, although he had been declared brain dead by three separate medical teams. In this case, the man had provided in his will that his organs could be made available for transplants, and approval had already been obtained from his family. Despite this, the police were determined that the doctors should not go ahead. They reiterated that brain death is not legally acceptable in Japan, and that they intended to make sure that the operation didn't happen.

Television viewers were treated to the sight of the police going into this hospital, running down the corridors with cameras following behind them, and the doctors backing up into the operating theater. Viewers were poised, waiting to see whether the police and cameras were going to crash through into the sacred space of the operating theatre or not. In the end, they decided not to and stayed outside, but it certainly made the point to the Japanese public that this is an exceedingly sensitive issue.

When one talks to Japanese doctors, it's very clear that they feel as though the public, the media, and the police are looking at them all the time. They believe that they are on stage with respect to transplant procedures, and are therefore concerned about pushing their side of the story.

The first definition of brain death was formulated in 1974 in Japan; that's only six years after the United States. In 1985, this definition was accepted by the Ministry of Health and a final report was issued in which the definition which is currently made use of in Japan was published. However, this report was explicit that "death cannot be judged by brain death." So, there is a definition of brain death and there's a diagnosis of brain death, and the diagnosis is quite often used in hospitals,

*Nooshi no  
mondai*

but it does not mean that brain death is the end of human life. The use of this diagnosis, therefore, has very little meaning because there's no urgency to move ahead to remove organs. The Japanese Medical Association, after arguing extensively, finally agreed that they would vote to accept brain death as the termination of human life, but when one examines the various subspecialties in Japan, it's clear that there is still disagreement. One important group, the politically active Japan Association of Psychiatrists and Neurologists, for example, remain opposed to accepting brain death as the end of life. Now this, of course, is very important. Many physicians in this group are neurologists and they are the people who are actually involved in making a diagnosis of brain death. Their explicit fear is that brain death, if equated with death, will lead to the slippery slope down which the handicapped, the mentally retarded and disadvantaged will be at risk, in a greedy desire to get at their organs. They also have stated repeatedly that it is difficult to establish brain death with complete certainty.

There have been some doctors, including one very flamboyant doctor at Tokyo University, who have joined a very active patients' rights committee which has gone public about the question of organ transplants. This group has targeted doctors with several law suits, for murder charges in some cases. One recent case involved a doctor, who is also a Buddhist priest, who had turned off the respirator of a comatose woman and removed the kidneys and corneas in accordance with a living will and with the consent of the family. Despite this, several doctors, together with the patients' rights committee, have taken this case to the public prosecutor's office and want a trial. So far none of these cases has been heard in court. The public prosecutor's office keeps putting them off and nobody's very surprised about this. What this situation does, however, is to keep everything on the boil. Nothing is settled. It's quite clear that the only way this matter can be settled is for a bill to go through the Diet, and for brain death to be enshrined in law as the end of human life. So far, this has not happened, although there is at present a private member's bill in the Diet, but it's unlikely to be heard in the near future, because, as we all know, the Japanese government have one or two other things to think about right now, like nerve gas and earthquakes!

A special cabinet committee has also met to debate brain death; there have been numerous forums and public debates; and there have been public demonstrations



in the streets. In other words, this is a very, very controversial issue which has caused as much furor, and perhaps even more than the abortion debate in North America. In passing, let me say that there has not been any similar action about abortion in Japan. Attention has focused instead on what is known as the “Brain Death Problem” (*nooshi no mondaï*), and that in itself is a very interesting issue.

Another point of interest to set up the contrast with North America, is that the Japan Federation of Bar Associations has maintained its position throughout that brain death is not death. This is in strong contrast to the American position, where the lawyers right from the start were agreeable with the AMA in saying that brain death is a medical diagnosis and not something in which lawyers should involve themselves. The Japan Bar Association is concerned about unforeseen consequences in connection with inheritance claims, and about a lack of public consensus on this issue. The Ministry of Justice has also spoken out against accepting brain death as the end of life, and while all these major institutions take these stands there can be no moving forward on the debate.

Groups, institutions, and individuals opposed to brain death usually cite as their principal cause of concern a lack of trust in the medical teams who are going to make the diagnoses. They believe that in the rush to retrieve organs, the process of dying will be curtailed or even misdiagnosed. The opposition is explicitly opposed to the secrecy and the arrogance of some members of the medical profession. They point out that patients and their families are vulnerable to exploitation. Certain opponents of brain death are at the same time pushing for informed consent, because this is not as yet routinized in Japan. The question of frank disclosure of information is something about which people are also arguing, but which is by no means settled. There is a real concern about the authority of physicians, and many believe that the medical profession is much too paternalistic, much too authoritarian, and that it's time some changes were made.

One of the biggest national newspapers, the *Asahi Shinbun*, described the medical world as “irritated with government dithering.” Doctors, particularly transplant surgeons, are disgruntled, believe that their reputations are at stake, and have said as much at meetings in Japan. The 1994 international meeting of transplant surgeons in Kyoto was a very dramatic event, a huge international

conference in which, among other celebrities, Tom Starzle, perhaps the most contentious transplant surgeon in America was brought in. The conference organizers asked him to make a public statement which would be transmitted from that conference directly to the Japanese government. Dr. Starzle did exactly what he was asked: he said that he thought that Japan was losing out, that as a very sophisticated and modern country they should have moved ahead with organ transplants long ago, that their hesitation was making them look out-dated, that they were going to be falling behind with respect to research and health care, and that, in effect, it was a disgrace that no organ transplants were being done in Japan.

Outside this huge meeting there were demonstrations by groups opposed to organ transplants. As an anthropologist doing research on this subject I found that I was in a difficult position because I had been granted free entrance to the conference, but I also wanted to participate with the group standing outside opposed to the conference.

Some of you may have heard a report the other day which came through on the radio that the Japanese have been working recently on introducing the human genes for blood into pigs. What they're aiming for are pigs that will have human blood in them, with the hope that they can then use pig hearts and probably other pig organs for transplant into humans with a low chance of rejection. This is one of the ways in which the Japanese have tried to get around the brain death problem. They have also tried to develop artificial organs, and make regular use of liver and kidney transplants from living donors. The Japanese have done more living donor transplants than any other country in connection with livers, and they have a very high rate of kidney transplants taken from relatives of the recipients. So there isn't opposition to all transplants in principle. The big problems are the source of the organs, the diagnosis of death, and the removal of organs from brain-dead bodies.

There has also, over the past twenty-five years, been a huge number of public opinion polls taken among the Japanese as to how they feel about the brain death problem. Over the years the number of people who recognize brain death as death has increased from 29% to approaching 50%, but it is agreed that 50% is by no means a consensus. These opinion polls are usually drawn on by those who are against brain death to support their argument, because they assert that consensus is necessary for

the green light. One is also left with the feeling voiced by many members of the Japanese public that the whole exercise of repeatedly surveying the nation is essentially a farce, and that the idea of trying to achieve a simple consensus on such an inflammatory subject is really without meaning.

Clearly, mistrust of physicians on the part of the Japanese public contributes to *nooshi no mondai*, the “brain death problem.” But one is left with the question of why this issue more than other pressing issues in connection with biomedical technology has captured the attention of the nation. Discussion about informed consent appears in the media; so, too, does information on the new reproductive technologies. Increasingly, there are articles about genetics and genetic technology. So far, none of these topics has been treated with the same importance or to the same extent as the question of brain death and organ transplants. What is also interesting is that debate in this area can be extremely vituperative—people become very angry. Sometimes the television programs about death lead to some scenes which are quite fascinating, because participants completely lose their tempers.

*The Problem of  
“Culture”*

There has been an enormous number of articles, books and newspaper editorials published on this subject, as you can imagine; one estimate claims that there are over five hundred books in Japanese. A perusal of these books reveals that certain sentiments are expressed repeatedly, such as “unnatural” (*fushizen*). Brain death is reported to be too unnatural to be called “death,” or is reported as being “contrary” to basic human feelings. The idea of controlling death is also described as going against nature. Organ transplants have been characterized in one book as *egetsu nai*, a powerful vernacular term indicating that something is foul, or ugly, or revolting. Organ transplants are also described as “bloody” and “unnatural.”

Arguments about the institutionalization of organ transplants requiring a brain dead donor seem to raise major concerns about interfering with what is assumed to be the inevitable, natural process of death and dying. For the most part these concerns remain largely unarticulated, or else articulated only as emotion-laden adjectives, or sometimes indirectly by means of allusions to the West, which is characterized as too rational, too cold, and having moved ahead without paying proper attention to human feelings.

Whereas an approach in which death is understood largely as a biological process, apparently devoid of culture, is, we *think*, widely accepted in Euro-America today (although some research is beginning to show that this is probably not the case), in Japan, clearly, people are concerned that death cannot be thought of as a rational process at all. Contemporary Japanese attitudes towards science and its associated technology are difficult to pin down because they are intimately linked to a widespread ambivalence about the process of Japanese modernization. Moreover, Japanese attitudes towards modernization can't be understood in isolation from ever-changing interpretations given both inside and outside the country about the relationship of Japan to the West. The form that the current debate takes about body technologies in Japan is shaped very much by what Japan knows about the West, and what images it holds of the West. The feasibility of tinkering with the margins between culture and nature and the very creation of those margins is part, I believe, of a more general concern about modernization, and a fear of excessive westernization on the part of the Japanese.

Some of the audience, I am sure, know very well that in Japan throughout the late 19th century an eager quest for Western science and technology was grounded in what Tetsuo Najita has called a "sense of cultural certitude," an awareness that the core or the bass note of Japanese culture would remain unaffected. Technology, self-consciously aligned with the Other, was placed in opposition to culture in this discourse, and epitomized by the platitudes *wakon yoosai*, "Japanese spirit and Western technology," and *tooyoo dootoku, seiyoo gijutsu*, "Eastern morality, Western technology." Najita and others have shown how this confidence in the endurance of culture was gradually eroded. Early this century, and again particularly after the Second World War, internal tension erupted over Japan's increasing technological sophistication and internationalization. Fears about an imminent collapse of the nation's cultural heritage became commonplace, and one reaction was an assertion of cultural essentialism. Throughout these transitions, although Japan undeniably remained a part of Asia, it nevertheless thought of itself as fundamentally different from all other Asian countries, particularly so because until relatively recently it was the only country in Asia to have successfully trodden a capitalistic path to modernization. So Japan has consistently and self-consciously set its culture off

from that of the Other, and continues to be regarded in turn by many outsiders as “inscrutable” and different.

One dominant theme in internal Japanese cultural debate over the past forty years has been the extent to which it is possible or appropriate to continue to cultivate a sense of uniqueness, of natural difference from other peoples. Not surprisingly, it’s usually those of a conservative persuasion who vociferously insist that Japan is inherently different from both the West and the rest of Asia. Conservative reconstructions of history suggest that the Japanese continue to be, as they have been from mythological times, naturally bonded together as a moral, social, and linguistic unit. The majority of Japanese take clear exception to the extreme form of this rhetoric, which slips easily into racism and xenophobia. But it’s evident that such a powerful discourse, at times explicitly supported by the government and inflamed by trade, whaling wars, and international peacekeeping disputes, cannot easily be dismissed *in toto*. Even among those who are not ideological extremists, fears about the malaise of modernity, of the attainment of material wealth at the price of spiritual and humanitarian concerns haunt many people in Japan (as do, of course, the people of many other nations). For many, the specter of Westernized individualism, utilitarianism and super-rationalism triggers emotional responses which can push Japanese commentators towards a rhetoric of difference even as, at the same time, they buck against its nationalistic and essentialistic underpinnings.

This is the kind of discursive background, to use the Foucauldian term, against which the brain death debate is taking place. Appellations such as “tradition,” “cultural heritage,” “religion,” and “animism” smack of superstition and pre-modern sentimentality to a very large number of people, but the waters are muddied because Japan is repeatedly described by certain internal commentators and outside observers alike as having undergone a unique form of modernization largely dependent upon the cultural construction of “special” human relationships and ideals of cooperation and harmony. It’s very difficult from within Japan to find a position from which to criticize or engage this debate. If one questions whether science and technology is perhaps going too far, one runs the risk of being lumped with the right-wing nationalists, as, indeed, at least one Japanese anthropologist and

myself have experienced in making an argument that culture may be involved, that there may be something we really need to discuss here about the resistance to brain death, rather than simply doctor-patient relationships. It's extremely hard to steer clear of the nationalistic rhetoric that is associated with this debate.

I'll just give you one extreme example. This is the kind of statement a well-known conservative philosopher has made repeatedly on television and in the books he has edited on the subject. Everybody knows this man is reactionary, but nevertheless he is taken seriously by many. Professor Umehara makes comments to the effect that Japanese people dislike transplantation because they don't adopt unnatural things. He says, "We have never in the past, accepted extreme Chinese customs such as foot binding and the eunuch system." In a similar vein he says, "Contemporary Japanese hate homosexuality and the use of drugs." Umehara lays blame for the sorry state of the West at the feet of René Descartes, for focusing attention on the brain as the center of the living person. Nevertheless, he believes that people everywhere are unique, rational beings, but concludes that "while Western Modernism makes us Japanese happy in one sense, it has destroyed our surroundings and nature." This is the kind of rhetoric around which people must try to negotiate to find a middle ground.

Many people argue that in Japan it's very hard to understand death as a point in time, that death is thought of as a process, and that it's something which people find extraordinarily hard to think of as an event, as is necessary if you're going to make a definition of brain death. Other people talk indirectly about the ancestors. Although they're often reluctant at first to admit that this might influence the problem, it is clear to me that the influence of the ancestors is present. The boundary between the social and the cosmic order has never been very firmly defined in Japan, as is the case for many societies. The ancestors are immortalized and thought of as continuing to act on the everyday world. They eventually become part of an animized natural order, and form a bridge between the social, natural, and cosmic domains. Many people whom I have interviewed believe that it is important to pay attention to the recently deceased, although not the entire ancestral lineage. They indicate that for the sake of the family, it is important to preserve the memory of parents and grandparents, to look after a dead body, and to go through the Buddhist

rituals in one form or another. Recent studies have shown that many Japanese also believe that there is a liminal period between the time when biological death takes place and the transformation necessary in order to become an ancestor, and that this liminal period is a very dangerous time, when people should be cautious. This is particularly true in connection with what is taken to be unnatural, sudden, or violent deaths, and this is of course often the case with brain death, since a car or plane accident, or a suicide is usually the precipitating incident.

There is another part of Japanese culture that no doubt influences the present impasse, having to do with the obligations involved in the giving or receiving of gifts among strangers. Furthermore, on a different track, the emotional center of the body has traditionally been located in the metaphorical space of the *kokoro*, in the chest region. The brain and the head are not usually thought of symbolically as the center of the body.

In closing, let me just return briefly to the West by way of contrast. I cannot take time to deal with the medical debate in the West, but I want to consider the position that a couple of American philosophers have taken as to where we should go from here. They are both writing with the assumption that in the West we currently have a “shortage” of organs, that we have to find more organs in order to further develop and expand this technology. As early as 1975, the bioethicist Tristram Engelhardt wrote that a definition of death as irreversible coma is a conservative definition. And he went on, “It takes more to be a person than reaction to pain, spontaneous respiration and reflex activity.” Engelhardt, rigorously following a mind-body dichotomy, believes that an intellectual decision has been made in defining death in terms of the brain, namely that human biological life is not the same as human personal life. He says that an otherwise intact and alive but brain-dead individual is not a human person. “We’ve grown up, since the development of modern neurology and neurophysiology,” states Engelhardt, “to take for granted the assertion that to be a mind in this world is to have an intact, functioning brain.” He then pursues his argument to what he sees as a logical conclusion, namely that a lack of *upper* brain function alone signals death, and therefore patients in a persistent vegetative state, not just brain dead patients, but patients like Karen Ann Quinlan with brain stem function, should also be thought of as dead. He says that

*Closing  
Arguments*

“the brain-oriented concept of death offers medicine a way of distinguishing between patients—i.e., the persons to whom medicine has obligations, and the collection of human organs, i.e., mere biological life—which can be used to help persons still alive.” Since there’s no obligation to organs, according to Engelhardt, no ethical quandary exists about the removal of organs from those who are defined as non-persons.

More recently, another philosopher, Robert Veatch, has argued that the definition of death is actually a debate over the moral status of human beings. He characterizes it as a debate about when humans should be treated as full members of the human community, when humans are living, and when full moral and legal rights accrue. Veatch believes that science can’t solve the problem of defining death, and that we are not likely to reach an easy agreement in a pluralistic society. He claims that a diversity of beliefs should be tolerated, that obviously we have to avoid violating the rights of others, but we also have to avoid creating insurmountable social problems for the rest of society. Veatch then argues that people would not be able to pick a definition of death which required society to treat them as dead even though they retained cardiac, respiratory, mental and neurologically integrated functions. He says likewise, “I assume that people would not be permitted to pick a definition that would insist that they be treated as alive when all these functions were absent.” He’d like to see a definition of irreversible cessation of the capacity for consciousness written into law as a third option for death. However, Veatch himself believes that the whole-brain orientation that we have at present is already old-fashioned and is becoming less and less plausible. He states, “To me, the principle is that for human life to be present, that is for the human to be treated as a member in full standing of the human moral community, there must be integrated functioning of mind and body.” He continues, “that means some version of a higher-brain oriented formulation.”

In other words, both of these philosophers want us to take what is often described as the slippery slope, where we seek to redefine death again and again, as we find ourselves in need of more organs.

The Japanese, obviously, come at this problem from a very different point of view, where they have been relatively unconcerned with the Cartesian dichotomy.



Nor have they had a concept of unique, clearly-bounded individuals in whom rights are unequivocally invested as part of their heritage. These topics are debated, of course, in Japan today. The idea of rights is currently gaining a serious foothold, but it has to battle against the still powerful flow of tradition in which an individual is conceptualized as residing at the center of a network of obligations so that personhood is constructed out of mind, beyond the body, in the space of ongoing human relationships. “Person” in Japan remains, perhaps for the majority, a dialogical creation, and what one does with and what is done to one’s body are by no means limited to individual wishes or individual rights. Moreover, self-determination is thought of as essentially a selfish exercise. Japan is also a culture which, as a result of its Buddhist heritage, always placed a great investment in the importance of non-verbal communication. Establishing rapport with another individual, especially a close relative, in which a oneness is achieved, often through touching rather than through language, is highly valued. As we’ve also seen, deceased relatives continue to play an important role for many people in daily life in Japan.

I think all of these factors contribute enormously to the brain death debate. The Japanese are steeped in modern neurophysiology, as are North Americans, yet not surprisingly, given the particularities of their cultural heritage, they’ve chosen to focus their concerns on the donor, on those who are brain dead, and the question of whether they are indeed dead, rather than on the heroics associated with the “gift of life,” which preoccupies us in North America. Ironically, activist groups against any changes in the definition of death in Japan often express their concerns by demanding that the “rights” of the brain dead be recognized. It will come as no surprise that when both Engelhardt and Veatch spoke at a bioethics conference recently in Tokyo, their talks confirmed what a good number of Japanese expected, albeit subconsciously, to hear—that America is indeed a land of extremes where people have apparently forgotten how to care about one another.

Thank you.

## Commentary

## **Professor Charles Leslie**

I was interested in the differences you pointed out between Japan and North America. You remark that North Americans are upset about killing fetuses, hence the abortion protest. On the other hand, we have routinized organ transplants. In Japan, abortion is a very common technique of birth control, but there is great sensitivity and revulsion about something that is routine in the United States—harvesting organs for transplant. This caused me to wonder about the nature of the organ transplant “market.”

I would propose that this kind of surgery was invented in the first place in response to a market for new biomedical technology and the rewards that it brings to the physician. Biomedical research and technological innovation are usually thought to involve “pure” motives: advancing science as well as helping restore sick people to functional roles. But the monster in the park is the temptation to murder people in order to harvest their organs, or to exploit poor people to get them to sell organs. Evidently a market exists in Japan since some transplant surgery is done there and some people go abroad for organ transplants. That market, however, is inhibited by circumstances: the murder indictment of the physician who performed the only heart transplant in Japan, and the authoritative medical testimony that the recipient patient’s heart was tampered with to make it appear more defective than it in fact was, and by cultural attitudes toward the body in Japan that differ from attitudes in North America, as well as a less heroic conception of physicians and their technology.

Professor Lock defines broad differences between Japan and North America while emphasizing the heterogeneity of bioethical reasoning and of attitudes in

both societies. The practical issues are: (1) how should decision-making be regulated by law? and (2) how might decisions be regulated by mobilizing public opinion? This means an effort to control the market. Who gets the organs? Whose organs are given to others? The gift is not cost free. This is very expensive surgery and, I assume, very profitable to some people and institutions.

What I miss in Professor Lock's paper, then, is the economics of transplant surgery.

Much would be spent on organ transplants in relation to other health-care expenditures. How is the decision made to expend resources on organ transplants instead of on school lunch programs, for example? When health insurance was being debated in the United States in recent years, we were told that Japan spends much less per capita than the United States on medicine. What regulates the market? How do organ transplants in Canada, where there is a system of national medical insurance, compare to the United States or to the United Kingdom? Clearly the system of insurance is important. Are organ transplants paid for by insurance or are they paid for privately? Do economic factors inhibit organ transplant surgery in Japan?

Professor Lock emphasizes the legislation of brain death as a way of creating donors for vital organs. The ethical argument, which she mentions elsewhere but did not mention in the talk, is that physicians who practice transplant surgery regret the large waiting list of people in the United States and the death of people who are awaiting transplants. This creates what many regard as a "pitiful" situation that we should do something about. Some have suggested redefining death to include people in a vegetative state, thus increasing the pool of potential donors.

Thirty years ago, Richard Titmus compared the systems of collecting and distributing blood in the United States and the United Kingdom and found some interesting points: (1) The US was largely commercial, the UK largely non-paid volunteer donors. The British system of making a gift of blood he showed to be more efficient than the commercial American system. There was less wastage of blood. There were fewer shortages of blood. There was less infection from blood transfusions with blood given as a gift rather than paid for. This was an example, in

Titmus' analysis, of virtue rewarded. It was an ethical innovation made possible by blood technology since the gift was anonymous. In marked contrast to all other gift relationships, it did not involve any possibility of either reciprocity or subordination.

The great traditions of medical practice in Europe and Asia were ethically grounded in philanthropy. The physician's gift of healing power was supposed to be untainted by pecuniary motives, and this tradition was not unknown in my small-town childhood during the Depression. Some physicians were known not to charge very poor patients and were said to ask a smaller fee from hard-pressed families than from well-to-do patients. Rural people, of whom my grandparents were an example, made seasonal gifts of farm produce to their doctors: apples, or chickens, or fresh eggs as the seasons changed. This was a society without medical insurance, and one in which people were known to each other. I am not nostalgic about it. Its cruelties and injustices were as cruel and unjust as any today in Berkeley. Everything changes, and medicine now is overwhelmingly a commodity.

The virtue of Professor Lock's paper is that she is alive to the circumstantial, shifting nature of the patterns which distinguish Japan from the United States. It is often said that Japanese society is much more homogeneous than that of North America, but she shows the heterogeneity in Japan, too. Thus, one expects that in the United States, driven as we are by the fetishization of life, life is more desirable than death—even life in an expensive nursing home strapped in a wheelchair and left drooling before a television set, or life in an intensive care unit maintained by the best medicine money can buy. Or maybe some of us will learn that everything living dies, and that "death is death; and for the dead, death has no attributes."

## Dr. Guy Micco

I'm going to speak, it will seem, not directly to Professor Lock's points, but I think my comments will be relevant to the topic. The great elephant of Death can be touched in many ways and in many places.

This is where I went after reading Professor Lock's materials.

Until the 1950s or '60s, death was an event, one which in theory was relatively easy to discern. The dying person stopped breathing. Breath had long been the key sign of and, in fact, equal to life itself. In many languages, the word for breath is equated with life and soul. The Latin word "spiritus" is one such, and it is from *spiritus* that we get our words "inspire" and "inspiration," to breathe in, and "expire" and "expiration," to breathe out and, interestingly, to die. In addition, breathing is something which is easily verified. You look at the chest rising and falling, you listen for the sound of air movement with ear to the patient's nose and mouth, and feel, again with ear to nose and mouth, for inhalation and exhalation. If these are absent for many minutes, then the dying person has died—not a tough diagnosis, if you're careful.

The other traditional vital sign, or sign of life, is the heartbeat. I've always liked the idea of death being equated with the stopping of the heart, it's just that, unlike breathing, the heartbeat may be difficult to discern. I have several patients whose hearts I cannot hear, even with my stethoscope listening very carefully. So, I think that King Lear had it right when he said, with Cordelia in his arms, "I know when one is dead and when one lives. She's dead as earth. Lend me a looking glass. If that her breath will mist or stain the stone, why then she lives."

So what happened in the late 1950s and '60s to cause trouble? The mechanical ventilator was introduced, as Professor Lock pointed out. Now a dying person about to expire could be given the miracle of the breath of life by a machine. How now to determine death? This would have been a problem, I think, even if organ transplantation had not been waiting in the wings.

In a classic paper in the journal *Science* in 1971,<sup>1</sup> physician Leon Cass responded to philosopher Robert Morison's argument that death should be seen as a process rather than as an event. Cass would have none of it. As he saw it (and I'm sure most physicians saw it), the death of an individual human being as an *integrated, functional whole* is what counts. This is a rather discrete event. In other words, we should not look to the death of the person's parts—their organs or cells—but rather to the death of the person as a whole, functional organism. Clearly, when a person stops breathing and no one and no machine breathes for them, or when their heart stops beating and no one resuscitates them, they soon cease to function as a whole, even if certain cells and organs continue to live on for a longer period of time. But what if a ventilator takes over the breathing and, if needed, the heart is restarted? Indeed, is it really the loss of heart or lung function that signifies the death of the whole, integrated, functional human unit? This is where the concept of brain death comes in.

I'll be talking about what's called "whole-brain death" or "the whole-brain criterion" for death. This is taken to mean an irreversible loss of all brain function, both the cognitive, conscious, awareness functions of the higher brain (the cortex), and the so-called integrative function of the lower brain or brainstem. Part of our brainstem's function is to cause breathing. If there is no brainstem, there is no breathing—unless it's artificially rendered. Another part of the brainstem function is to somehow make us awake, but not consciously aware. Awareness requires a functioning cortex.

People with intact brainstems but with no cortex activity are breathing and awake, but are not conscious of the fact. This condition is called a vegetative state, and it is how Karen Quinlan spent the last ten years of her life, and how Nancy Cruzan spent the last several years of her life. They were not brain dead by current standards; they had functioning brainstems and 'dead' higher brains.<sup>2</sup>

If it weren't for the invention of mechanical ventilators, we might not have this new criterion for death because, as you know, without brainstem life, there's no breathing; hence, a traditional death. Despite this fact, whole brain death as death is compelling. In theory, it is very accurate, as accurate or more so than the old "Are you breathing?" or "Are you beating?" criteria. The rigorous criteria for whole brain death leave little room for mistakes, although mistakes can always and everywhere be made, and unlike the heart or lung standard, it's virtually 100% predictive of irreversibility. There is the additional benefit, if a benefit it is, of knowing that medical science can in no way, whether by machine or transplant, restart or replace a brain. This is one reason why the whole-brain standard of death has been accepted in the United States. In forty-nine of fifty states, in fact, whole brain death equals death. Another reason is, as Professor Lock has noted, for most of us in the United States, the center of the self, in fact our very being, is located somewhere in our grey matter (cerebral cortex). This is where we think that we think, feel, interact with our environment, and even have religious experiences.

I thought we'd do a cultural thought experiment,<sup>3</sup> which I hope will not be too gruesome. Suppose it's the year 2195. In 2195 your life expectancy would be about 600 years. You have a terrible accident in which you are decapitated, but an ever-ready RoboMedic immediately hooks your head up to an artificial blood supply pump and your neck to an old-fashioned mechanical ventilator. Your heart continues to beat in your lower body as it's ventilated by the machine. Your brain continues to be conscious in your head. You are transported in two parts to a healing center. Unfortunately, because of the nature of your accident, the surgeons are unable to put you back together. But, they do have a donor body, from the neck down, artificial or real—your choice. You take the artificial one because it feels 'unnatural' to be attached to someone else's body. You request that your lower body be removed from life-support and buried, because you do not want to be a donor. The surgeons then attach the artificial body to 'you'—your head. Any problem? The whole brain death as death formulation could be applied here: The lower part of your body while it was being maintained by a ventilator was the equivalent of a whole-brain dead patient as it is defined in 1995—a body sans head or brain.



This type of reasoning has been used to suggest that permanent cessation of whole brain functioning is the best and really the only necessary and sufficient definition of death.<sup>4</sup> All this is regardless of organ transplantation. I think it highly likely that we would have come to the whole-brain criterion for death even without the perceived need for donor organs.

Despite this, Professor Lock has led me to wonder why, death being a rather major subject, there wasn't more of a debate in our society about the change from heart-lung to brain criteria. Professor Lock has noted that in Japan one part of the complex cultural reasons for the dislike or at least ambivalence for the whole-brain standard is a mistrust of doctors. The first and only heart transplant in Japan in 1968 by Dr. Wada clearly didn't help in this regard. As you remember, Dr. Wada defended himself against charges of murder for six years before being acquitted, and Professor Lock has said that the majority of Japanese in retrospect believe that the patient whose heart was removed by Dr. Wada was not really brain dead. This was not good.

Given the distaste for authority, including the paternalistic medical authority of the time in the United States which was becoming an issue in the 1960s and '70s, if we had had a Dr. Wada-type case, I suspect there would have been considerably more debate. As it was, however, unlike the fears and distrust in Japan that physicians might prematurely take an organ from a not-yet-dead donor, in the 1970s, physicians in the United States were being publicly criticized for keeping patients alive *too long*, for not allowing so-called "Death with Dignity." This criticism was not uncalled for. A common attitude among physicians in the United States then was that if you could save someone's life, say with a ventilator, then you were obliged to do so. And even more common was the notion that it would be unethical, even illegal, to stop a ventilator or other life-sustaining treatment once it was begun, regardless of what the patient or family thought about it. These attitudes of both physicians and the public have radically changed since the 1970s in this country. In the 1980s, a new and very different problem arose. Some patients' families began to feel that everything that could be done wasn't being done for their sick loved ones. In a complementary turnabout, some physicians began to complain that patients and families were pushing them to deliver what they called "futile

care,” including unnecessary (in the eyes of physicians) use of ventilators and other life-sustaining technologies.

Now, after about eight years of this, the first such case has gone to court in Massachusetts just this month, wherein doctors wrote a do-not-resuscitate order for a supposedly severely and irreversibly brain-damaged patient against the family’s wishes. The patient then died without CPR being performed. Her daughter has sued the physicians at Massachusetts General Hospital for, to quote the New York Times on April 3, “mental anguish she said she suffered because, she asserts, her mother’s fervent wishes were not followed.”

This is a very big case and is representative of a very big medical and medical ethics issue in the United States called the “Futility Debate.”<sup>5</sup> In this new climate, a case such as Dr. Wada’s heart transplant in Japan might well cause a furor, not just a debate, over how the concept of brain death is used in the United States to procure organs or to save money. However, I doubt the concept of whole-brain death as death would be assailed because of this.

This is not to say that there are not problems with the current brain death standard. There is still considerable confusion among physicians, nurses and the lay public about it. This is perfectly understandable when we realize that the purportedly dead-brain dead person can look and act very much alive. This is not the place to delineate all the things that a supposedly dead brain can do. Suffice it to say that a dead-brain person can manage, with some help admittedly, to gestate and be delivered of a healthy child, a rather amazing feat for an individual who has supposedly lost her ability to function as a whole, integrated human unit (being thereby ‘dead’).

An occasional family at the community hospital where I work will, at least initially, refuse to allow the ventilator to be turned off on their brain-dead relative. Sometimes this is due to physician or nurse confusion about the diagnosis of death. In a conference in Frederick Weisman’s excellent six-hour documentary film called *Near Death*, nurses in the intensive care unit at Harvard’s teaching hospital, Beth Israel, talk about a family’s inability to accept the fact of the death of their brain-dead loved one. I have a few quotations from that film that, I suspect, could come from any hospital in this country. Here three nurses are speaking:

Nurse #1: We went to school for four years to understand this. I had a hard time when I first came here. "Brain-dead." I'm like, 'Yeah, but the heart's beating, and. . .but wait a minute! But they're really dead.'" And then when I learned about the Harvard Criteria,<sup>6</sup> I even had a hard time, and I'm a nurse. And I'm sure the families have a hard time. In a one-hour conversation with the docs to say, "Yeah, he's dead. But we're going to take the tube out, and that's that." And they're like, "But. . .but. . . wait a minute!"

Nurse #2: You are also the person who is taking care of the person who is dead but alive. You somehow add to the confusion when you continue to take care of someone who they, the family, understand as dead. I think you're gonna get the heat. You're gonna get a tremendous amount of rage. I mean, you took care of them. They're dead, but they're alive, and now you're going to end their life.

Nurse #3: We were attempting to make it easier on the family. We essentially controlled when we let the person go. They came in on a Sunday and they were brain dead on a Wednesday. And we manipulated it by adding stuff. Everything was manipulated to keep her going so the family could get the consults in and could deal with it. Now, did we make it any easier for that family? Not as far as I'm concerned, because when the end finally came for them, it was no easier on a Wednesday than if they had dealt with it right from the start.

In part because of this kind of confusion, some are pushing for what is called the "higher-brain" criterion for death to supplant a whole-brain one. The higher brain is the cortex, the presumed site of our consciousness and, some would have it, of 'ourselves' as human beings. Professor Lock referred to Robert Veatch, bioethicist, who is a serious proponent of this formulation. He claims that it is the higher brain that subserves "integrated functioning of mind and body." This integrated functioning requires the magic of consciousness. Once consciousness is permanently lost, we need not necessarily treat that person as a member of the human community. But, as Professor Lock pointed out, Veatch realizes that this is a non-medical question. Veatch writes: "There is no scientific way in which the debate about death can be resolved. . . . [It] is fundamentally a moral, philosophical or religious determination, not a scientific one."<sup>7</sup> His final answer allows for our

cultural diversity. We (our society) should allow patients to choose any of the three major options for death determination: heart-lung, whole-brain, or higher-brain.

My preference, a combination of Veatch and others, is to define death differently for different purposes: for purposes of turning off life-support machinery, for purposes of organ donation, and for purposes of burial. I would also, along with Veatch allow room for some individual patient/family decision-making. For instance, it should be acceptable, as it is now, to turn off or withhold life-support *whenever* the patient would want this. But, physicians might be allowed to turn off or withhold support unilaterally (without the informed consent of the patient's family or surrogate) once it was determined that the patient had irreversibly lost all higher (cortical/conscious) brain function. When could organ donation proceed?—when there was demonstrable death of the whole brain (the same criterion we have now). When could burial proceed? Or, as Halevy and Brody put it in a recent medical journal article<sup>8</sup>: When can the undertaker begin his services?—when the patient's vital signs or 'signs of life,' heartbeat and respiration have permanently ceased.

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- 1 Morison, Robert S., "Death: Process or Event" and Kass, Leon R., "Death as an Event: A Commentary on Robert Morison." *Science* 173, 694-702, 1971.
  - 2 For an up-to-date review of the concept of the 'persistent vegetative state'—loss of cerebral cortical function leaving a state of "wakefulness without detectable awareness"—see the report of the Multi-Society Task Force on PVS, "Medical Aspects of the Persistent Vegetative State." *New England Journal of Medicine*, 330, 1449-1508 and 1572-1579, 1994.
  - 3 Bernat (in Robert Joynt, ed. *Clinical Neurology*, Vol. 1, Chapter 3 "Ethical Issues in Neurology") references a similar "graphic demonstration" initially proposed by D.A. Shewmon.
  - 4 James Bernat, Professor of Neurology at Dartmouth Medical School, is a strong proponent of the notion that "death is best defined as the permanent cessation of functioning of the organism as a whole." The criterion of death which best fits this definition is, for Dr. Bernat, "the permanent cessation of functioning of the *entire brain*" (emphasis mine). For a review of this position, see Bernat, James L., "How Much of the Brain Must Die in Brain Death?" *The Journal of Clinical Ethics*, 3, 21-28, Spring, 1992
  - 5 Since this talk was delivered, the jury in the 'futility' case mentioned has returned a verdict finding for the doctors. However, those familiar with this problem will know that it is highly unlikely to be resolved by any one court case. The problem involves such basic issues as patient (and surrogate) autonomy, the 'integrity' of the medical profession, physician, power and control, the utilization

of (scarce) resources, and a cultural fear of dying and distrust of authority. For a look at the burgeoning literature on futility see Youngner, Stuart, "Who Defines Futility?" *Journal of the American Medical Association*, 260, 2094-2095, 1988; Youngner, Stuart, Futility in Context. *JAMA*, 264, 1295-1296, 1990; Schneiderman, Lawrence J., et al, "Medical Futility: Its Meaning and Ethical Implications." *Annals of Internal Medicine*, 112, 949-954, 1990; Jecker, Nancy and Pearlman, Robert, "Medical Futility: Who Decides?" *Archives of Internal Medicine*, 152, 1140-1144, 1992; Truog, Robert D., et al, "The Problem With Futility." *New England Journal of Medicine*, 326, 1560-1564, 1992; Veatch, Robert M. and Spicer, Carol Mason, "Futile Care: Physicians Should Not Be Allowed to Refuse to Treat." *Health Progress*, 22-27, December, 1993;

- 6 The "Harvard Criteria" were first published by the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death in 1968 (*Journal of the American Medical Association*, 205, 337-340, 1968). These "criteria" are a series of tests for characteristics (like absence of breathing and lack of responsiveness) which signify "a permanently nonfunctioning brain." In slightly altered form they are still used today.
- 7 Veatch, Robert M, "The Impending Collapse of the Whole-Brain Definition of Death." *Hastings Center Report*, 23, 18-24, 1993. (See also Veatch's "Brain Death and Slippery Slopes," *Journal of Clinical Ethics*, 3, 181-187, Fall 1992) Veatch seems to accept the definition of death as the permanent loss of an organism's ability to function as an integrated whole. He sees, however, major inconsistencies in the whole-brain criterion to fit that definition and believes that the higher-brain criterion is superior. He writes that for a human organism to function as a whole "there must be coordinated integration of two types of function: organic and mental. . . . If these two are irretrievably disjoined, then human life no longer exists." This, of course, would occur with permanent loss of the 'higher' brain (the cerebral cortex) which would render one irreversibly without consciousness (e.g.: in a persistent vegetative state, deemed permanent).
- 8 Halevy, Amir and Brody, Baruch, Brain Death: Reconciling Definitions, Criteria, and Tests. *Annals of Internal Medicine*, 119, 519-525, 1993. Halevy and Brody, like Veatch, point out problems with the whole-brain criterion for death; however, they do not accept the higher-brain criterion either. It is "unclear [to them] why humans have to maintain conscious functioning to be alive. . . ." And they find it objectionable that a patient in a vegetative state, without consciousness but still breathing, could be buried—this objection being based on "an intuitive understanding that such patients are not dead, even if they have lost their conscious functioning." Halevy and Brody suggest, like Morison in 1971, that death is more of a process than an event. With this formulation—that one might be 'dead' in different ways for differing purposes (see my text above). Again unlike Veatch, Halevy and Brody claim it justifiable to unilaterally withhold or withdraw life-sustaining treatment from a patient with "irreversible cessation of conscious functioning" (higher-brain death). They claim this not with an appeal to any criterion of death, but rather because "the need to rationally use societal resources outweighs the desires of some persons for unlimited care." But his claim cannot merely trump other counter-arguments involving a patient's (or their surrogate's) autonomous right to decide when life-sustaining treatments be withdrawn. This is a part of the ongoing national debate on 'futility' and will not be decided anytime soon.

# **Legalizing Physician-Assisted Death**

*A Skeptic's View*

**Alexander Morgan Capron**

with commentary by

Mr. Stephen Jamison

**Alexander Morgan Capron**

## **Legalizing Physician-Assisted Death**

Physician-aided death is a term that encompasses both euthanasia and assisted suicide. It is a broader topic than euthanasia, at least in the way that many people use the latter term to refer to active euthanasia. My talk today will focus on the practical matters and policy implications of legalizing physician-aided death. I will focus on physician-assisted acts and the question of legalizing physician-assisted actions, not on individual suicides or cases where a terminally ill patient is suffocated by a relative or non-physician.

*Introduction*

Although the title's reference to physician assistance suggests a focus on the role of the professional, the usual way of discussing the topic—and one that presents a more compelling case for action—is to speak of a patient's right to die in a particular manner. This right is usually seen as being manifest in four different ways. First, and most basic, is the right to a dignified death, as free from pain and suffering as possible, a right that precedes the organization of the professions and even the creation of societies, a human right—not just a legal right that transcends national boundaries. Second, the American system protects a legal right to control one's own body and to engage in private conduct. Third, a right to die is sometimes described as a constitutional right that might be thought of as the process by which our government translates fundamental rights and moral concerns into legal precepts. Finally, it can be thought of as a moral right in the patient's relationship with others, principally with members of the family and with healthcare professionals of all kinds.

*Patients' Rights*

I don't plan to say much of anything about the first manifestation of this right, although I recognize that in some ways it is the most interesting and difficult to debate. Nor will I dwell upon the latter, the moral right in relation to family and physician as such, although that issue might be seen as providing a backdrop for my comments. Instead, I will focus on the question of whether society ought to recognize, as a matter of positive law, the right of individuals to the assistance of

physicians in bringing about their own deaths free from the threat of regulatory, civil or criminal sanctions. My attention will thus be on the law, but primarily I want to focus on the policy implications of moving toward a broader conception of the legal right to physician assistance in dying.

*The Medical,  
Cultural and  
Legal Setting*

Legislative efforts have already directed a good deal of attention to the issues of active euthanasia by physicians and of the physician's role in directing and assisting suicides. But before turning to the examination of these efforts, I think it is helpful to consider the cultural setting in which these issues have come about.

Examining several factors may help clarify why the topic of physician assistance in dying has become prominent. First, advances in medical technology and the consequent aging of the population have led to an increase in cases of chronic illness in American society. Second, most people presently view death as a medical event. Eighty percent or more of Americans will die in a healthcare institution, either in a long-term care institution or an acute-care facility. As recently as fifty years ago, only a small minority of people died in those circumstances.

This huge increase in the medicalization and the institutionalization of death and the dying process has had significant consequences for the medical profession. Medicine is commonly seen as deeply implicated in, even responsible for, a good deal of the dying process. Medicine's ability to secure longer life expectancy has brought with it a greater incidence of debilitating conditions that can be sustained with medical intervention. Prolonging the length of the dying process by reversing acute threats to the patient's life and by providing artificial support of kidneys, breathing, heartbeat, and alimentation has placed a much greater burden of responsibility on medical practitioners in determining the course and quality of our deaths. Finally, some see medicine as responsible for creating the level of apprehension that attaches to this subject—the terror with which many people now confront the question of death—because we have come to fear that this technology will be applied without the consent of those most immediately affected by the event of death. Patients and their families often experience an anxious lack of confidence that, even if the attending physician could be persuaded to stop, the law or institutional policy would take decision-making power out of the patient's or the family's hands. Furthermore, there is another anxiety that once a physician has



diagnosed a terminal condition, he will simply say, “There’s nothing more that I can do,” when in fact there is always something more—at the very least, to provide relief from pain and a comforting presence.

Despite physicians’ delight in their high technology, the American Medical Association prints on its checks that famous 19th-century etching of a physician sitting in a parlor with a sick child stretched out on a makeshift bed. A lamp is lit, but the morning light coming through the window indicates that the physician has spent the night worrying whether the child would survive its fever. Of course, the physician’s presence probably did little to influence the outcome of the illness. There was no meaningful intervention: the doctor’s bag probably contained little more than a stethoscope and maybe some digitalis. But the presence of the physician and his importance, not just to the comfort of the parents looking on anxiously from the doorway, but to the child’s survival, is unquestioned in the picture. Unfortunately, such an image does not come to mind very often for dying patients today. It is that sense that the physician is going to disappear from the scene, and in particular will not do all that can be done to relieve the pain and reduce the suffering of the patient, that implicates medicine with the subject of death in a rather negative way. Ironically, the expectation among physicians, as well as among patients, is that modern medicine should have a magic bullet for everything. That fascination with the magic bullet is also behind some of what is pertinent here. At the same time, there is another element that I like to think of as the “Nordstrom factor.” Many Americans view medical care not just as a matter of human rights, but in consumerist terms—that is, one should be able to purchase what one wants and “the patient (the customer) is always right.”

Aside from medical developments, recent cultural and legal history has also influenced the way many people view physician-assisted dying. A strong American commitment to individual rights and to privacy in this field has translated into the law of informed consent and even into constitutional protection for choice and freedom from bodily interference without consent. Beginning with landmark cases such as the New Jersey Supreme Court’s Quinlan decision, courts across the country, including the United States Supreme Court, have recognized that both the common law and the Constitution protect the right of a competent adult to decline

any medical treatment, including artificially provided life support, alimentation, or hydration. These cases are described, wrongly in my view, as “right-to-die” cases and are central to this discussion. Additionally, all states have enacted positive laws in this area and have either a durable power of attorney or a healthcare proxy statute (which California pioneered in 1983 with the first Durable Power of Attorney for Health Care statute) and/or a living will statute, (which California also first adopted in 1976 as the Natural Death Act).

Underlying all these factors is American’s meliorist disposition. We always desire to make things better. We always think that if we press on, we will find a new frontier where things will work out. This impatience with limits, no doubt, leads Americans to a great deal of ambivalence when confronting death.

There are additional factors, surely, but these should help to clarify why the topic of physician assistance in dying has become so prominent today. Public opinion polls confirm that a strong majority of Americans favor giving people rights to make decisions about their own dying, including the right to get their doctor’s assistance in bringing about death.

This public support has led to several recent efforts, at the ballot box and in the courtroom, to move this public sentiment into law. Let me first describe those efforts that have focused on removing the legal barriers to active euthanasia with physician assistance and to physician participation in assisted suicide.

*Active  
Euthanasia:  
California and  
Washington*

**I**n November 1991 in the State of Washington and in the following year in California, ballot measures were put before the electorate to authorize active euthanasia by physicians. The California initiative in particular would have authorized mentally competent adults to request in writing “aid in dying,” which was described as medical assistance in achieving a medical procedure that would terminate life in a painless, humane and dignified manner, either administered by a physician or provided to a patient for self-administration. The statute would have required a terminal condition to be diagnosed, and it established rules for executing, witnessing, and revoking the request. If properly requested, the statute authorized physicians to terminate life and provided them with immunity from criminal or civil liability for participating in that process. It allowed physicians, healthcare profes-

sionals and privately-owned hospitals to refuse assistance in dying if religiously, morally or ethically opposed thereto. It also specified that asking for, or providing, this assistance was not to be considered suicide and it prohibited the existence or non-existence of directives affecting the terms of insurance policies, or their sale, renewal or cancellation, or the level of premiums that could be charged in the event that policy holders chose not to request active assistance after being diagnosed for a terminal illness.

The proposition had a number of features; one in particular bears mentioning: its use of the “advance directive” format used in living wills. To fill out an advance directive, patients had to be “qualified.” They had to be mentally competent and diagnosed by two physicians as suffering from an irreversible condition that would result in death within six months. An advance directive makes sense as a means for a non-competent person to direct what medical steps should be taken when he or she can no longer make decisions. But in the Proposition 161 context, in which actions depended on a patient remaining competent, a written directive could have only two effects—either to put a person into the position of being committed to going through with euthanasia, despite a change of heart, or of setting the stage for a statutory change that would allow euthanasia of incompetent patients.

After the defeat of these initiatives in Washington state in 1991 and in California in 1992, both by 54 to 46 margins, the proponents of legal change concluded from an examination of the polls that the electorate wanted stronger safeguards and more limited power for physicians. Oregon’s law, which was approved in 1994 by a 51 to 49 margin and is now being held in suspension by a federal court order, gave doctors less control than previous proposals. [Subsequent to this lecture, the court voided the statute as unconstitutional on equal protection grounds.] It legalizes physicians’ aiding suicide, particularly with their prescription pads, but leaves the final act to be performed by the patient. The law applies only to legal adult residents of Oregon who, in the opinion of an attending or consulting physician, “have the ability to make and communicate healthcare decisions”, including “communication through persons familiar with [their] manner of communicating if those persons are available.” To be qualified to obtain a lethal prescription, the patient must also be suffering from a terminal disease that has been

*Assisted  
Suicide:  
Oregon*

“medically confirmed and will, within reasonable medical judgment, produce death within six months” .

The definition of “terminal” as a condition that will lead to death within six months has a particular bureaucratic history. When plans were being made to extend Medicare benefits to hospice care, the majority of patients being considered for hospice were cancer patients, for whom a life expectancy prognosis could be reasonably made. In order to limit access to hospice in an actuarially sound, predictable fashion, the decision was made to define “illness” as a condition that would result in death within six months. Plainly, the major consequence of making an error in predicting death in a patient who lives beyond six months is limited to Medicare having to pay for more hospice services than projected. In physician-assisted suicide, the gravity of the consequences are self-explanatory; an error would result in the death of someone who was not near death. And the likelihood of mistakes in prognosis are great, since predicting the time of death is always difficult and at six months is highly unreliable, especially outside of the field of cancer.

*Safeguards*

Beyond the requirements of adult age, mental competence, residency and terminal disease, the Oregon statute contains four principal safeguards: informed decision-making, a second medical consultation, psychological consultation if needed, and repeated, verified oral and written requests. Discussions of the Oregon initiative seem to accept the proposition that its safeguards would provide an adequate shield against the potential abuses that frightened many voters in other states. In my view, many of the law’s requirements provide less protection than is commonly assumed. Certain implied safeguards are unlikely to limit the practice of physician-assisted suicide in the manner that is claimed by proponents. For example, the residency requirement will not stop people from other states from availing themselves of the law, since residency is simply a matter of intention.

Similarly, the roles of the attending and consulting physicians are not closely monitored. Any doctor—including a pathologist like Jack Kevorkian—could qualify as an attending or consulting physician as long as that person is qualified to practice medicine in the state. Nor does the statute provide for an independent consulting physician. Both the attending and consulting doctors could be partners

in the same specialized suicide practice. The protection against suicides induced by mental illness or depression is likewise a thin reed. First, counselors need not be independent of the referring physician. Second, the statute explicitly states that a mental evaluation is necessary only when one of the physicians, who need not be trained in psychological evaluation, requires one.

I am also concerned that, ironically, assisted suicide statutes are more likely to produce inappropriate actions than are euthanasia statutes. For example, under assisted suicide statutes, the physician's involvement is reduced merely to writing the prescription and giving it to the patient. Acting at this moral distance, the physician may actually feel less of a psychological or ethical impediment to ending a patient's life. Most physicians would probably be more reluctant to give a patient a lethal injection that would be the direct, immediate cause of death than simply to write a prescription that the patient will self-administer later. Additionally, the Oregon law's requirement of repeated requests for aid over fifteen days are in some ways irrelevant, since the law allows a patient to obtain a lethal drug and then administer it much later. By that time, the competence and voluntariness of the patient, who might be under pressure from a spouse or relative, could be radically different than it had been in the physician's office. Indeed, what guarantee do we have that death is a suicide rather than a homicide? At the risk of being judged overly cynical, I believe that today more people come to bad ends at the hands of their friends and relatives than they do at the hands of physicians. The abuse suffered by elders, spouses and children are just some examples.

Finally, and perhaps most important, the assisted suicide statute does not provide adequate protection from expansion. What will happen if a minor or a person who is physically unable to ingest drugs wishes to avail himself of the statute? Moreover, why don't patients who suffer from slow, painful illnesses like Alzheimer's disease fall under this statute? In all three of these cases, the patient has a moral, and perhaps legal, argument as to why the statute should be expanded. I will return to this issue again later in the discussion.

**I**n some cases, the drafters in Oregon were responding to other complaints that critics had raised about the Washington and California initiatives. The first objection is that the attending physician must lay the basis for an informed decision

*Other Concerns*

by the patient. Specifically, this must encompass information not only about the diagnosis, the prognosis and the “potential risks associated with and the probable results of taking the prescribed medication,” but also the feasible alternatives, including but not limited to comfort care, hospice, and pain control.

In a certain way, the requirement to be told the potential results of taking the medication might seem rather superfluous in this context: the patient is asking for something to kill himself. The requirement seems an effort to accord with the general law of informed consent: if you’re going in for an operation you want to know what the risks and side effects might be. But if the requirement is taken seriously here, one has to recognize that there is little clinical, pharmacological knowledge about self-administered means of suicide, which have, of course, never been an object of scientific study.

Closely connected to this concern about the role of the physician is another of the central safeguards cited by proponents of change in physician-aided death. Advocates of these statutes claim that changes in the law would not create a regimen of death on demand for everyone, but are restricted to this sub-category of terminally ill individuals. An analogy is frequently drawn to terminally ill people who are on life support and who have the authority under law to insist that treatment be withdrawn and that they be allowed to die.

Advocates of these initiatives recognized, nevertheless, that physicians are fallible. The concurrence of a second, independent physician would provide some, but not a perfect, remedy for this problem. Two heads are better than one, but both may be wrong; and the medical errors will be self-correcting. When a patient who mistakenly receives a dismal diagnosis with a false prognosis of imminent death decides to forgo treatment, the correct diagnosis is likely to become evident in time. Whereas, if the law permits the patient to decide that a lethal injection is preferable to six months of life with that illness, the medical error becomes self-fulfilling instead.

*Reliability of  
Prognosis*

**I**n any event, fallibility in diagnosis is probably less of a risk than the mistakes that will occur in predicting that the patients will live no longer than six months. Indeed, many physicians regard predictions of death more than a few days, or even a few weeks, in the future as exercises in the grossest kind of guesswork. There are

so many things that can happen to patients, particularly those whose pain or other symptoms are adequately addressed, that would render a prognosis of six months much too short in many cases. Thus, no real protection is provided by this requirement that a six month prognosis be rendered with reasonable medical judgment

Herbert Hendin, president of the American Suicide Foundation, describes a patient who was referred to him.

A few years ago, a young professional in his early thirties who had acute myelocytic leukemia was referred to me for consultation. With medical treatment, he was given a 25% chance of survival; without it, he was told he would die in a few months. His immediate reaction was a desperate preoccupation with suicide and a request for support in carrying it out. He was worried about becoming dependent and feared both the symptoms of his disease and the side effects of treatment. His anxieties about the painful circumstances that would surround his death were not irrational, but all his fears about dying amplified them. Many patients and physicians displace anxieties about death onto the circumstances of dying: pain, dependence, loss of dignity, the unpleasant side effects resulting from medical treatment.

Once the young man and I could talk about the possibility or likelihood of his dying—what separation from his family and the destruction of his body meant to him—his desperation subsided. He accepted medical treatment and used the remaining months of his life to become closer to his wife and parents. Two days before he died, he talked about what he would have missed without the opportunity for a loving parting.

Under the Oregon law, he probably would have asked the doctor's help in taking his own life. Because he was mentally competent and did not meet the clinical criteria for a diagnosis of depression, he would have qualified for assisted suicide and would surely have found a doctor who would agree to his request. Since the Oregon law, using guidelines like those in effect in the Netherlands, does not require an independently referred doctor for a second opinion, he would have been referred by a physician supportive of assisted suicide to a colleague who was equally supportive. The evaluation would very likely have been pro forma.

He would have been put to death in an unrecognized state of terror, unable to give himself the chance of getting well or of dying in the dignified way he did.

Hendin here puts a human face on the concerns of voluntariness, failure to recognize depression, and fallibility that I think we cannot ignore. Furthermore, this is not a matter of abstract questioning about our sliding on a slippery slope. It seems to me that Oregon Ballot Measure 16 can provide no protection against a greatly-expanded practice of euthanasia. For example, there will be pressure to expand the statute to minors. In the reproductive context, courts have insisted that pregnant minors have a protected privacy or liberty—a right to choose. This right can be limited, but it cannot be eliminated solely because of the patient’s age. So too, advocates for minors with fatal illnesses will insist that they are also entitled to choose aid-in-dying without being subject to a parental veto.

Likewise the initiative sponsors insist that it is limited to those who have exhausted all treatment options because the statute defines “terminal” as a condition that is incurable or irreversible. Yet under existing California law, patients are free to accept or reject any treatment option, even when it might be life-saving. Thus, it can be expected that some patients diagnosed with treatable conditions—for example, cancers—that would be fatal within six months if *not* treated, may insist on a quick death rather than accept treatments that could prolong their life or even cure their disease.

The expansion is something that we can see from the case of the Netherlands. Hendin writes in his article in the *New York Times*, “Virtually every guideline established by the Dutch to regulate euthanasia has been modified, or violated with impunity.” A healthy but grief-stricken social worker mourning the death of her son two months earlier was assisted in suicide. A man in his thirties who is HIV-positive but who has no signs and may not develop them for years was also helped to die without any effort to address the terror behind his desire to end his life. Euthanasia in the Netherlands, intended as an unfortunate necessity in exceptional cases, has become almost a routine way of dealing with serious or terminal illness, even with grief. A statute passed last year codifying guidelines provides additional protection for doctors, but not for patients.



My criticisms have addressed the particular language and the provisions of the enacted Oregon statute and the proposed California statute. These points might seem like lawyers' quibbles. I think, rather, that it is not unfair to hold proponents to the language of their proposals. Moreover, it seems to me that the problems in those proposals are not the result of sloppy drafting. They are, instead, inherent in the tension between the desire on the one hand to have narrow limits, safeguards and strict review, and the fundamental interest on the other hand in controlling one's own life and dying process. Those desires are fundamentally in conflict. While it is the latter interest that concerns most people and leads to support for the legalization movement, the language of these measures attempts to cabin that fundamental right and insist upon all sorts of protections.

*The Risk of  
Proliferation*

The risk goes beyond the supposition that legalizing one set of activities will only press us inevitably to expand, as has been the case in the Netherlands. Any attempt to insist upon oversight and controls intrudes the state more deeply into individual decisions, a situation that can be illustrated by the failure to attend to the issue of pain. Proponents of right-to-die statutes recognize that the Dutch guidelines (and commentators) have insisted that euthanasia be practiced only in cases of unrelievable pain, but such a requirement has not been written into the American proposals. Why not? I suggest that the propositions' drafters recognize two things. First, it is very difficult to include a definition of pain because the experience of pain is subjective. In fact, one of the problems we've had in getting the medical profession to address pain sufficiently has been that it *is* so subjective and that if it can't be quantified objectively, physicians don't know that it's there. I exaggerate a bit to make a point—increasingly, doctors are learning that they have to take their patient's complaints about pain seriously. For example, scales have been developed where a *patient* can grade his or her pain at a given time.

*Pain*

Second, there is still a problem with the role we would allow pain to play. Are we going to have a regimen in which, if your pain is not severe enough, you would not be allowed either active euthanasia or assistance in suicide? If so, we would have the prospect of legal or institutional challenge: people might object in particular cases by claiming that the person's pain is not sufficient. Challenges like that would force cases into the courts, which would have the courts deciding whose pain qualifies whom for a voluntary death warrant.

In effect, we would have socially sanctioned judgments about quality of life: what kind of life is worth living? Who can be told that they cannot have the state-sanctioned release from suffering because their pain is not great enough? The prospect of that happening is real enough that people are reluctant to include statutory provisions for pain. If these provisions are not included, however, and if the terminal illness requirement falls away because of ambiguities surrounding diagnoses and prognoses, the prospect becomes the very real *probability* of euthanasia or assisted suicide on demand. That may be what people are comfortable with, but we should be very clear that *that* is the inevitable tendency of these sorts of statutes.

*A Final Caveat*

I do not think that the decisions of the voters, or of the district court in Washington, will provide the kind of guidance that I would want to follow. More compelling was the report issued last May by the New York Task Force on Life in the Law, *When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context*. They set out what seemed to me to be very good reasons for maintaining the laws that prohibit this aid, whatever one may think of some exceptional cases. Not the least of these reasons is to protect vulnerable people from being pressured to end their lives. No one is more vulnerable than a sick person. It is a very short distance from the triumphant right to control the time and manner of self-death to the felt obligation to accede to the apparent preferences of one's caregivers and end all this misery.

The image of rational suicide is clearly refuted by the evidence that the New York task force gathered. Suicide is rare among the terminally ill. Most patients who commit suicide do not suffer from terminal conditions, but from treatable mental or emotional distress which their families or their caregivers may not recognize.

The appeal of an easy death is undeniable, and there is much that physicians can but don't yet do to make death less painful and more a part of a dignified ending to life. In all probability, legalizing physician aid-in-dying would undermine rather than reinforce the progress that has been made in the right direction toward addressing patients' pain, not with the magic bullet of death, but with the almost magic bullets of pain control. The last thing we should want is to accept the sort of

conduct that Lord Devlin suggests may have occurred with the patients of Dr. John Bodkin Adams, who was acquitted nearly forty years ago of murder. In the words of Lord Devlin:

He might have murdered—it must be remembered that euthanasia is murder—either as a mercy killer, or perhaps just to finish off a troublesome patient who was dying anyway, and for whom he could do no more.

## Commentary

## Stephen Jamison

I am very taken with Alex's comments on multiple grounds. I find myself, most interestingly, looking at my own emotional reaction to this. I was the regional director for the Hemlock Society here in Northern California for several years and very active in the 1992 California ballot measure. Recently I finished a three-year research project on family-assisted suicide, primarily in the US and Great Britain and some in Germany. From the perspective of distance and from no longer being associated with or paid by the Society or involved in the politics of the Right to Die movement, it is beneficial to me to examine the emotional reaction I have now. I've found myself both angry with and agreeing with many of Alex's points.

I just checked my answering machine before coming here. It had an emergency message from an eighty-six-year-old woman in Oakland. She said, "Please call me. I know we just met the other day to talk about the death of my husband. I have carried this terrible loss for four years. Today is the fourth anniversary of his death."

Four years ago this woman in her mid-eighties assisted her husband to commit suicide. It was a horrible decision that the two believed they had to make; it was more horrible for her than it was for him. Although he was able to escape what he considered the suffering of Parkinson's Disease, he was *not* terminally ill. They were living in a retirement facility in Oakland and were being forced out of it. They had been given orders to move him into a convalescent facility or both of them were going to be evicted from the residence.

Twenty years earlier they had made, and had reconfirmed over the years, an assisted suicide agreement if such a case should arise. There were several terrible

aspects of this death. She ended up having to use a plastic bag to suffocate him, as was agreed if he could not put the bag on himself. He was not able to; he fell unconscious with the bag around his forehead, and needed her help to complete the task.

She was one of the initial interviewees in my research. Since then I have studied 140 assisted deaths and have interviewed many more people who have participated in assisted suicides. Some of my findings correspond with the points that Alex has made, but some of them do not. I have found that the pressures that lead to these kinds of decisions often materialize in the reverse fashion. Family members are the ones often pressured to help a terminally ill patient die. This happens especially when terminally-ill patients take a very strong stand that this is the form of death they want. They may insist that *they* are the ones dying, that everyone else is surviving, and that this is the last thing their loved ones can do for them, and that they had “damned well better do it,” as it is often expressed.

Granted, 140 deaths is a limited sample, but my findings showed some common features. First, physicians were involved in only one third of all cases. Second, physicians assisted by providing prescriptions—in some cases inadequate prescriptions—to end the patients’ lives. Third, there was no counseling, no second consultations. In these instances, physicians seldom discussed these cases in depth with the patients or the families. And fourth, many of the doctors were family practitioners who had longstanding relationships with the patients involved, but they were not necessarily specialists in the diseases from which the patients were suffering.

While my research did not finally solve the problem of assisted suicide, it did locate some common problems involved in this issue, both with cases involving and those not involving physicians. My comments today are highly informed by that project and by the research of others, especially in the AIDS community in the San Francisco Bay Area.

There is broad public support for aided suicide. According to opinion surveys, approximately two thirds of the public support a change in the law concerning assisted suicide. Moreover, there is broad support among physicians; over fifty

percent in some surveys similarly support changes. Physician surveys show that as many as forty percent indicate that they would help a patient in this manner if the law were changed. As many as thirty percent, thirty-two percent in Great Britain, admit to having assisted in at least one case.

It already exists. Physician-assisted dying already goes on—without counseling, without support mechanisms, safeguards or alternatives. It was interesting to find in my research that of the 140 assisted deaths I studied, 125 of them were listed as natural deaths. Suicide and assisted suicide does exist among the terminally ill, it's just covered up. These are people who do *not* go out for counseling, who a third of the time have already made prior arrangements with their physicians, and who may have reached agreements about what should appear on the death certificate. Frequently these are people whose physicians just shrug off the actual cause of death or don't know, but who are not inclined to question a family of a possible suicide or assisted suicide when they have just lost a loved one. If there is any chance that the person—for example an AIDS case who has had a bout of pneumocystis pneumonia or someone else in the late stages of a terminal illness—dies, the doctors will sign the death certificate without calling in a coroner or requesting an autopsy. It happens regularly.

Another thing that I found in my own study was that pain was not a major issue. It paralleled what the Remlink report found in the Netherlands, which was that pain by itself comprises a small percentage of reasons for requesting an assisted death.<sup>1</sup> The Netherlands study showed that less than ten percent of requests were for pain alone. These very nebulous other factors—such as quality of life or intolerable suffering, which do not necessarily involve pain—take precedence.

I found very similar results. People are often just tired of living after being treated for several months, after intolerable suffering from factors like an inability to swallow, an inability to breathe, tumors in their throats, KS lesions in their stomachs, having to choose between feeding tubes or being hooked up to intravenous alimentation, and so on. These are not choices to these people. It's not pain that they are experiencing but a general discomfort that they have found intolerable. Incurable diarrhea, for example, may not qualify as pain but, in conjunction with other symptoms, it is not something many people want to live with.

But does this mean that we should legalize physician assistance in some blanket fashion? No.

I have not come full circle, but my views on this issue have changed significantly. I believe that the propositions that we have had over the past few years have been driven by a Civil Libertarian perspective that suggests very strongly the tension that Alex noted before between balancing the fundamental interest in controlling our own lives and the need for narrow limits and safeguards on the other. I agree with Alex on this point.

Who drafts these measures? Attorneys. Who are they supported by? Primarily by right-to-die activists who are primarily very healthy at the time. They may indeed have experienced a very significant loss in their family, something they don't want to go through themselves, something they are angry about. They often see the Civil Libertarian perspective as providing an answer to that loss or that anger.

Unfortunately, perhaps, we need safeguards for doctors, and we need safeguards for ourselves. I believe that we need to have legalization, but that we need to have it in a way that provides very strong controls. I think we need to start out very slowly and have a place where we can examine it, judge it, and assess it. We need to act cautiously before we loosen it to a point where it becomes available to those who indeed are intolerably and incurably ill.

Currently, people are required to follow their disease to its natural conclusion. They then have to ask their physicians for illegal help, or they ask their families, which is frequently the case. Instead of a situation like this, we could have assisted dying as a legal right. I would argue, however, that it should be provided in a way that balances the needs of patients, physicians, and families, as well as the larger medical community, while safeguarding all parties from wrongful actions. I do not foresee that it will ever be available simply upon request. I believe that it must be reserved for extraordinary cases that fail to respond to efforts at palliative care. Moreover, it must be provided in a way that promotes an ideal of medical intervention that carefully looks at each case and carefully balances a patient's suffering with the principles of Beneficence, Non-Maleficence, Autonomy, and Justice, which are the four principles of bioethics.



In light of this, I would make several recommendations for change. I propose the implementation of strict guidelines that would establish criteria for determining which patients would qualify for assistance as well as strict guidelines for clinical practice that would protect both health care providers and patients. These would ensure that a patient's condition is intolerable and irreversible, that available options for care have been attempted, the patients' motives have been fully explored, counseling opportunities have been provided, and that issues of rationality, and both social and family dynamics have been addressed.

Second, I would recommend that the only way this kind of legal action could be implemented would be to make changes in existing homicide statutes to include criminal penalties for both assisted death and mercy killing so that if a case falls outside of narrow guidelines, criminal prosecution would still be possible. Similarly, mercy killing statutes could cover cases on non-voluntary active euthanasia like the Roswell-Gilbert case in Florida, where a man shot his wife who had Alzheimer's.

Mercy killing cases are oftentimes handled lightly by the courts, but I think we need to leave them in the hands of the courts to provide for appropriate criminal penalties. In cases where motives are determined indeed to be altruistic and disinterested, penalties might be minimal or nonexistent. These would also be available for family members who decided to help another family member to die, as already happens quite frequently. But we need to have a lessening of criminal penalties, or a court that is very lenient in such cases. None of this, however, means that we should just allow it freely.

Third, I think the real problem is how to permit this practice and still avoid all the problems that Alex has brought up in terms of patient-physician privacy, suicide clinics and all these other matters that are not problems we can just wipe away or ignore. One solution might be the formation of appointed or *ad hoc* bioethics committees at hospitals, regional medical associations, or local hospices that would be charged with overseeing the practice of assisted dying. These committees would receive and review detailed, in-depth reports from physicians on each case, advise physicians on difficult cases in terms of clinical procedures and guidelines, standards of care, and the qualifications of patients, assess reports from physicians, and pass

on these findings to state medical licensing boards or other governing bodies for data collection purposes.

These kinds of committees, however they are designed, might well include a representative of a law enforcement agency: the coroner's office, the medical examiner's office, for example, such as is the case in the Netherlands where cases go before the prosecutors and each case is potentially prosecutable. I think that we need something very similar here to remove that fear of widespread abuse. Such a committee might include a local hospice medical director, hospital and hospice social workers, or nursing personnel in addition to those I've already named.

Each case should be handled confidentially to protect patients, but there is a delicate balance here in terms of protection. What I have in mind is that we need to prevent the kind of Dr. Gunn episodes that we see in cases of abortion in Florida and elsewhere. The team approach ensures that both the decision-making and assisted dying processes are open to some level of scrutiny. In addition, these committees could oversee continuing medical education efforts locally on issues involving pain control and end-of-life care.

Fourthly, a patient requesting aid in dying from his or her primary care physician would be immediately referred to a hospice or to a consulting physician trained in hospice care. This would be an appropriately-skilled physician trained in palliative and hospice care, not an ophthalmologist or someone with a biased interest in physician-assisted dying, like Dr. Jack Kevorkian.

Ideally, I would like to see hospice be the institution primarily responsible for this practice within the community. Why? Because it already has trained nursing personnel, medical directors, and the best available training in palliative care. More importantly, it has social workers and others who can perform family assessments. These skilled practitioners can be brought together in a team approach that prevents the kinds of abuses that may or may not occur in Alex's version of the worst-case scenario.

This is not the, but an answer. We cannot continue to allow the current abuse—which is non-legalized physician aid-in-dying without counseling, without family assessment, without an assessment of motives—continue as it has. This may be

opposed by physicians. One physician has told me that he endorses physician-aided dying but is opposed to any kind of legal change. He thinks physician-aid-in-dying is good medical practice, but that the legalization could invite unwanted scrutiny and meddling. This is the dilemma. Doctors don't want anyone else looking over their shoulders, but if the decision can be taken out of their hands either by giving it to a healthcare team or by requiring committee input, they would be freed of the anxiety that comes with an additional burden to their professional responsibilities. The decision to provide aid-in-dying would, in these circumstances, become something that they could refer to another decision-making process.

I think we also need to roll back a lot of the decisions and practices we already have in effect in terms of withholding or providing life-sustaining treatment. A lot of these kinds of decisions as well as a lot of the double-effect kinds of decisions—death via morphine overdose, for example, which is used for pain control and as a means of masking non-legal active euthanasia in hospital settings—need to be clarified in terms of end-of-life care and bioethical decision-making. We cannot consider euthanasia, either active or indirect, as a case that needs to be looked at separately from providing or withholding life-sustaining treatment, which, I should point out, is the one complaint that the Dutch have against their own system of euthanasia, and which constitutes a large percentage of complaints about unnecessary deaths. Euthanasia, as defined under Dutch law, includes withholding life-sustaining care, something that seems to bother us in California not at all. I think it should start bothering us, and I think we need to come together and work on a commission that looks at all end-of-life decisions and puts these all together in a package that guarantees that futility of care is examined, that all end-of-life decisions meet certain basic criteria, and that we finally have some kind of consistency in such provisions.

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1 P.J. Van der Maas, J.J.M. van Delden, and L. Pijnenborg, "Euthanasia and Other Medical Decisions Concerning the End of Life: An Investigation Performed upon Request of the Commission of Inquiry into the Medical Practice Concerning Euthanasia," *Health Policy Monographs*, Vol. 2. (Amsterdam: Elsevier, 1992).

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