

# EUTHANASIA POLICY IN THE NETHERLANDS

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## MEDICINE AND HUMANITIES [E]MERGING DEFINITIONS

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# Euthanasia Policy in the Netherlands

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## Euthanasia Policy in the Netherlands

First of all I would like to thank the Townsend Center for the Humanities for inviting me to address you today on the subject of euthanasia as it is practised in Holland. I will speak for about thirty minutes, and then I hope you will respond and that we can together arrive at some appraisal of my comments. I will not bombard you with statistics, but will rather provide you with some examples, some close-ups, from my own experience.

If I may say something about myself: I work as a geriatrician in a chronic care facility, an institution not quite comparable to an American nursing home, because in the Dutch variety there are a number of resident physicians. This means that patients are not moved to a hospital or a hospice when they enter the last stage of life. Doctors working in Dutch nursing homes consider it their task to look well after the dying, and they consider palliative care as part and parcel of their medical expertise. Indeed nursing homes are often used and advertised as hospice care facilities.

I will distinguish three stages in the history of euthanasia in Holland in the last 30 years a history that evolved from initial tentative clumsiness to the now accepted legal structure. There is plenty of comment within Holland about the nature of these proceedings but the internal debate rarely reaches that particularly abusive level often encountered in the international arena where Dutch euthanasia policy is usually met with unrelenting disdain.

I am not in the exporting business and would like to emphasize that I am not here to promote anything. I merely wish to inform you as honestly as I can about certain aspects of the tremendous difficulty of dying well. It's a difficulty well worth thinking about, because, though I said I would refrain from statistics, I think it might be helpful to remind you of the percentage of patients who ultimately die. It is 100%, in Europe, at least, and I have every reason to believe that the same percentage obtains here.

Before entering into details I must offer you a definition: in the Netherlands we use the term euthanasia when a patient is being handed or administered, at his or her explicit request, a lethal dose of medication in order to end his or her life. For the purpose of this talk, physician assisted suicide is included in the definition. It is allowed by law under certain narrowly prescribed conditions into which we shall enter later.

In Holland, before 1980 roughly speaking, you could describe the proceedings around deathbeds ending in euthanasia as belonging to the underground period. One of the more fascinating questions, the answer to which can only be speculative, is why there was no question of euthanasia in the fifties, when there was just as much dying going on. Several factors account for this: important changes in doctors, patients and diseases.

In the first half of the twentieth century doctors typically came from the higher social levels, and this social distance aggravated the inequality that is always there between a doctor and his or her patient. It is almost unthinkable that a patient under those circumstances would dare to utter a plea for death; it would have been seen as an act of defiance, or insubordination, and would never have been interpreted as a cry for help.

With the coming of the sixties a new generation flooded the universities. They came from the lower middle class or working class sections of the population and were a little less convinced of themselves and

their intrinsic worth. They did not tower so highly above their patients and found it less easy to ignore the desperate pleas that came to their ears.

A second factor is the increasing power of Intensive Care Medicine. Two historical deathbeds greatly influenced thinking and feeling in Holland about death and dying. I mean the horribly protracted agonies of Franco and Tito. Franco died in 1975. Tito in 1982. Both these statesmen for political reasons had to be kept going after their virtual deaths. The reason was that within the several factions queuing up for the throne some in-fighting had to be concluded so that a definite successor could step forward at the very moment when the leader was declared to be definitely and entirely dead.

Now, the staving off of this moment involved a terrifying interlude in intensive care units for these two dictators whose failing bodies were dragged across a series of hurdles ever more difficult to negotiate as organ after organ ceased functioning. Renal, pulmonary, and ultimately cardiac failure was battled by increasingly drastic measures before the victims were finally let go into death.

I remember the feeling of awe and fear as millions watched this degrading spectacle and concluded: this is NOT going to happen to me or to anyone I care for.

Until 1980 then, things were done in a pretty clumsy fashion. Half voiced requests for euthanasia were answered in ways that were only loosely formulated. As for what doctors actually did at that time, I will offer you the history of Mr. Johnson. He was 55 years old when I met him and a very bitter man. He was suffering from lung cancer and had been undergoing treatment over two years, two agonizing years, which for all he knew, were to end in his final discharge and a glorious return to a life he was very keen to resume.

Mr. Johnson was married and had two sons 17 and 22 years old. To his utter despair the oncologists, after torturing him for two years with horribly drastic regimes, turned their backs on him and said, in so many words: the game's up, we ran out of poison, you're going to die. I am giving you *Mr. Johnson's* way of looking at these developments. When I met him he was in a rage and actually demanded death. He found it impossible to forgive the oncologists for not telling him that despite all their horrible interventions he was still going to die.

I didn't know how to counter his fierceness, or how to alleviate his bitterness. The trouble in those years was that you couldn't openly discuss cases with colleagues without involving them in a pact of secrecy they might not want to be part of.

Of course looking back I would say that I should never have gotten mixed up in Mr. Johnson's revenge on life. I should have stood around and waited for him to find a milder tone in which to say his goodbyes to his sons and his wife.

What I did however was to supply him with an overdose of barbiturates which he was to take on a particular evening with his sons there in the room with him, and his wife waiting at home. Because I did not dare to be present for that would raise suspicion, I too sat at home waiting nervously for the call to come through that he had died.

I can assure you I felt just as you would if you were involved in such a situation: clumsy, guilty and scared about leaving those two boys there with a father who was going to die by his own hand.

We did not register anything of what went on, there was no chance for an independent colleague to throw a cool glance on the proceedings, nothing was examined before or after the event, we did not report to anybody. It all happened on the basis of the unique intuition of this one doctor urged on by a dying man or woman and assisted by a circle of family and friends who vowed they could keep a secret. The Law was

nowhere in sight.

You can imagine, or maybe I should say, you have no idea of, the extent to which people can fall into making mistakes when they are not guided by principles agreed on in a communal fashion. I am also referring to the technicalities involved here. I know of situations where people had to wait for days before death came, because the doctor gave them too low a dose. Or, the other way round, if the doctor used too acute a method, relatives felt their dear one had been kicked off the planet. It may sound a bit bizarre but it does involve some skill to let a person die gently.

Then there was the uncomfortable possibility that the doctor would opt out at the last moment, a development against which it was useless to protest, for the whole thing was against the law anyway.

Inevitably the world outside wanted a say in all this and an intense public debate came about in the shape of polemics, demonstrations, sermons, essays and a seemingly endless stream of documentaries and talk shows: a veritable river of comment that gained momentum over a period of roughly 30 years and finally overturned certain ingrained ways of doctors' dealings with the dying.

During the second phase there was a gradual development toward a clearer formulation of the criteria under which euthanasia should be allowed. Patient organizations, politicians, members of the judiciary, a rather timid delegation from the medical community, and a very imposing contribution from the Dutch Society for Voluntary Euthanasia, came up with guidelines. Euthanasia remained illegal but under certain conditions exceptions would be allowed: the patient must be terminally ill, suffer unbearably, and have no prospect of possible improvement. Within reason all treatments of the symptoms must be considered. The request must be durable and consistent and must not be uttered in the course of a psychiatric disease such as depression or dementia. The request must be written down by the patient. An independent colleague must be called in to check these criteria. Death must be brought about in approved fashion. The entire procedure must be reported to the authorities in the shape of the police. The police or coroner will discuss the report (after the euthanasia has been performed) with the Public Prosecutor and they will instantly decide whether the case fulfills the criteria or not.

In this second phase, starting around 1980, these criteria were gradually adopted and modified. The problem now was that public prosecutors were eager to explore the boundaries within which euthanasia would be acceptable. The underground years were in a way not quite so scary for doctors because no acceptance by the authorities was sought; now, as a doctor, you actually had to hand yourself over to their discretion. And you never knew when you were going to be dragged into the glare of publicity if some public prosecutor thought that he could sharpen his legal tools on your case.

Due to this threat of legal action, euthanasia acquired a faint touch of the heroic. An unfortunate example from this mock-heroic period is a case that was televised. A Dutch GP had himself filmed as he looked after one of his patients, an elderly man who was terminally ill at home with Motor Neuron Disease, Lou Gehrig's Disease as it is called in the United States. The man asked for death and his doctor accepted his request. I think all the criteria were more or less met in this case, and in that sense there was nothing unfortunate about it.

But they filmed the very last scene, and to film a person actually dying was not only felt to be shocking; it was also considered a breach of the dying man's privacy. The film was sold worldwide and though I do not doubt the motives of the makers, they were disastrously wrong about the impact their film would make. It did not put the doctors in the class of medical heroes. Quite the contrary: the film placed the entire Dutch

euthanasia policy in a most sinister light and Dutch doctors were seen as death-obsessed professionals doing beastly things to their patients.

What I personally found very hard to take in this phase was the involvement of the police. It was pretty ghastly to walk out of a tearful gathering that included the most decisive goodbyes that can be voiced in this life, and walk into the steely gaze of a police officer asking, “was there a lot of money involved? “I suppose they couldn’t wait any longer”? “Took too long to die, did it”?

These are questions that might be relevant when we think of murder, but these of course were not cases of murder—if only because the “murderer” was so keen to discuss the whole thing with the authorities.

Police officers finally disappeared and were replaced by the coroner, a medical colleague who would explain the case to the Public Prosecutor on the spot and thus make possible the release of the body. This meant that the distance between the doctor and the judge in cases of euthanasia was considerably enlarged. The criterion of being terminally ill was also dropped, because only in retrospect can the state of being terminal be ascertained with certainty.

During the third but as I will explain not final phase, from say 1995 onward, the role of the coroner remained the same but, the Public Prosecutor now receded into the background and was replaced by a Regional Committee consisting of a lawyer, an ethicist and a physician. The Committee reviews all reported cases in the light of the accepted criteria and when in doubt they can still decide to ask a doctor for a more detailed explanation. The Committee can also decide that a case calls for legal action and hand over the case to the Public Prosecutor.

Let me give you an example of a case in which I was recently involved that I think demonstrates how far we have progressed from the rather murky doings of the past.

Mrs. Williams as I rename her, was a childless widow of 82. She suffered a stroke and was admitted into our nursing home. She was paralysed on the left but her mental functioning was largely unimpaired. She could not stand, she could not walk, she could not get into bed or go to the toilet on her own, but she struggled bravely to regain her independence in order to return to her apartment in town.

However she did not make any headway and repeatedly spoke to her niece, devoted daughter of her one sister, about the possibility of euthanasia. Six months after admission she fell on the toilet, which, in spite of our warnings, she had tried to use by herself; and sadly she broke her hip.

When she came back from the hospital where she had been operated on she said: “This has gone far enough, I want to die. I know now I will never get out of this place and I hate being dependent on other people for every office of my daily life. I find it demeaning.” Added to all of this too, due to severe visual impairment caused by the stroke, she could not read or watch television.

Surveying the criteria I concluded that Mrs. Williams had a right to ask for euthanasia. She was suffering unbearably at the prospect of never regaining her independence again and having to wait for death during for an unpredictable number of years. Her request was put in writing and I judged it durable and consistent.

There was a snag however when we came to the point of a possible psychiatric disease.

In hospital she had also asked for death, and the response had been to place her on anti-depressants, a form of medication, which is grossly abused by doctors who seem to think that these pills will help against

despair. Having been prescribed the medication,

Mrs Williams was tainted with the dark suspicion of suffering from a depression, a suspicion eagerly seized on by doctors as a reason for refusing euthanasia. This is the perfect example of a Catch-22: anyone asking for death must be suffering from a depression, and this must be treated until they stop asking for death.

We called in a psychiatrist who, unsurprisingly, found Mrs. Williams not depressed, but pretty sorrowful.

On the appointed day at 11 am I entered her room in the company of a younger colleague who had been involved in her treatment and found her there in the company of her niece, Angela, and a nephew. I was anxious and she noticed my agitation and said: "Oh dear, are you nervous?" I certainly was—quite unlike her, for she turned to her niece and said: "I don't remember that blouse on you yesterday."

Mrs. Williams drank the potion I had brought with me without much ado but unluckily a couple of drops went the wrong way and she started to cough. The cocktail is bitter, sharp and sweet and ideal for a coughing fit. Since she had already downed half of it I told her to desist from further drinking. Meanwhile her niece sat on the bed, gently stroking her, while Mrs. Williams entered on the following monologue: "Do you think Gerard will be thinking of me now – remember the enormous portions of ice we took at Blenheim in the summer – ice extinguishes the alcohol you said – I sure hope God is a man, Angela, I may be all right then. I was pretty good with men. Angela, don't you think?"

At that moment, to my everlasting embarrassment my cell phone went off. "Shame on you doctor," she laughed, and then mentioned the title of the song in my ring tone to Angela.

This went on for about two minutes and then she closed her eyes and drifted away. We relaxed our attitudes a little, someone sighed, and at that moment she spoke her last words, with a hint of a smile, saying: "I'm still thinking!"

*Ergo sum.* But no, she was not quoting Descartes. The sentence just occurred to her.

This dying while talking is a rare occurrence and a mixed blessing for it creates strong anguish in the souls of the on-lookers. It is as if you are watching someone heading straight for the edge of a precipice and you know this must end in disaster, while you stand there, hands tied, eyes riveted, knowing there's nothing you can do to stop it. The dying do not experience this at all because they know that at the end they will not be staying behind in a room with a dead person.

After 45 minutes Mrs. Williams was deep in coma but still had not passed away. I had promised her that if this occurred I would give her a lethal injection, and she died soon after that.

Now, with my younger colleague, I left the room and felt a certain relief. But he didn't say a word, and as we strolled down the corridor I looked at him and saw that he was trying his best not to cry. We quickly went to my room where he gave up trying, and I realized anew that euthanasia is a terrible thing.

May I add that the Regional Evaluation Committee found my actions to be in accord with the law. Some final remarks:

The slippery slope. People say that once you allow euthanasia in a certain type of case, there will be no stopping its being applied to others as well. You never know where that may end. I wouldn't worry about this slippery slope, because once you've started discussing the right to suicide or the possibility of euthanasia, you're right ON it and you'll never get off.

I see as a distinguishing feature of an ethical debate the realization that you ARE on a slippery slope;

that is what being human is all about, all the more so now that there are no longer any Gods watching over us to whom we might turn for a definitive comment on our actions.

In Holland we moved down on the slope by giving up the criterion of terminal illness; then mental pain was allowed to be just as unbearable as physical pain. And recently a Dutch doctor supplied a ninety year old man with an overdose who was not ill at all in a strictly medical sense but had, in his own words, "been forgotten by death" and begged his doctor help him end his life. The case was brought into court and the doctor was sentenced provisionally and at the same time complimented by the court on the cautiousness with which he had acted. The doctor had reported his doings to the Public Prosecutor.

There is more to come. Dementia is THE present day scare amongst people of my generation and they are trying to introduce an advanced will type of document, specifying NOW that they want euthanasia LATER in case they lose their minds and cannot ask for it. I do not, by the way, think that this can be arranged, but people do talk about it.

Let me look at some foreign reactions to what is going on or rumored to be going on in Holland.

On a television program in Scotland I was in all seriousness asked to comment on the fact that in Holland old people live in constant fear of their lives, because when involved in an accident and carted off to a hospital they are very likely to get killed by the doctors there.

You can see it happening can't you? Lady falls on street, doctor greets her in the emergency room and says: "Well you broke your hip, and I am going to have to end your life." Of course it doesn't happen that way. The critics never tell you HOW this happens, nor do they bother to name a doctor or a hospital in which these unspeakable occurrences take place.

When I was in Japan explaining euthanasia in Holland people would listen quietly until I came to the passage where I related how a certain patient chose her own music for the occasion of her death: they were appalled. To them it seemed like arranging your own hanging, which is bad enough, but to opt for a certain bit of music to be played at the occasion is simply beyond what they deem comprehensible.

A BBC reporter visited me for an interview for the radio. While talking we strolled around the nursing home where I work in Amsterdam. He was favorably impressed by the level of care, the dedication of the staff, the facilities offered to the patients etc. And then he asked me, on behalf of his audience of course: "It seems to me that the people here are being cared for in an exemplary fashion. Now isn't that a contradiction to your euthanasia policy?"

I was stunned and said to the reporter: "Now what do you expect? That, next, I am going to show you the gas chamber in the basement?" There's always a whiff of mass murder in the air when certain questions are raised about euthanasia. The reporter left my response out of the broadcast, because it was a religious program.

In Germany the term euthanasia is forever poisoned by the Nazi program of that name, in which thousands of people were murdered for being identified as mentally handicapped. Present day Germans find it almost impossible to believe publicly in euthanasia as a humane possibility. When a Dutch survey showed that only 50% of all cases are being recorded in Holland, the German press seized on this as a clear sign that the thing had spun completely out of control. In their outrage they forget that the number of reported cases in Germany is zero.

I regret that I cannot tell you all I would like in 30 minutes. But let me conclude with two statements: First of all I do not believe that Holland has solved the problem of euthanasia. If we have achieved

anything it is the growing realization, also recognized internationally, that there is such a problem.

Secondly, I would like to point out to you that I would rather die in a country where palliative care is practised at a sophisticated level and euthanasia forbidden, than in a country where euthanasia can be easily arranged but where doctors do not know how to look after dying patients.

Thank you for your attention.

## Commentary

MICHAEL RABOW, M.D.

Thank you, Dr. Keizer. My comments really stem almost entirely from your last statement. I think the most relevant question in the United States is whether we will have good palliative care, but a law against euthanasia. Currently, I would say we have a law against euthanasia in every state in the country. Euthanasia is defined more narrowly as active ending of a life by another person, as opposed to physician-assisted suicide. The distinction has been made clearly in the United States, even in Oregon, where physician-assisted suicide is legal, euthanasia is not. So we do live in a country where euthanasia is illegal. But the question is whether or not we're going to be a country where palliative care is practiced routinely and well. So these are interesting issues for people in the United States to pay attention to, especially when considering the issue of euthanasia in Holland.

First, most Americans aren't aware of the options for palliative care, and for addressing distress at the end of life. Most Americans tend to see the issue as a black or white issue: fear about dying in the ICU versus the macabre image of Dr. Kevorkian. Perhaps it's an American trait to see things at the extreme. The reality sits between the two extremes in the vast majority of cases, and most Americans don't pay attention to their right to make an advanced directive, to communicate to family and friends what they might want in future situations, to communicate to their doctors, and probably most importantly to appoint a surrogate decision-maker to help them make decisions if they become unable to do so.

The options that we have are numerous but to look at this issue of euthanasia in Holland or the United States we have to ask what are goals are. What are the patient's goals when he or she is at the end of life? For many, this has been to live longer. Right? The phrase that we often use is 'Everybody wants a good death, just not now.' But if we pay attention to goals, and look at what the data suggest for the goals of those requesting hastened death in the United States, we see that very often those goals are about gaining some control over the dying process. In many ways, the phenomenon of Dr. Kevorkian in the United States arose out of a movement to gain control over dying, with most Americans feeling they had very few options to gain this control.

In fact, the options are more extensive than physician-assisted suicide or euthanasia. They include advanced directives, but they also include aggressive pain management, something that the United States has only come to relatively recently. The United States Regulatory Commission and the Joint Commission on Accreditation of Health Care Organizations only recently required that pain was an issue to be addressed in all hospitals that receive federal funding, which is essentially all hospitals, and that pain was to be assessed frequently and dealt with. So one of the first rights that Americans need claim is to good pain control.

There's also the issue of withdrawing or withholding life-sustaining intervention. Many Americans may not be aware that they have a right, legally-backed by the Supreme Court, to request withdrawal of mechanical ventilation, of dialysis, and significantly, of artificial nutrition and hydration. Another alternative that has been bandied about in the literature is the voluntary cessation of food and fluids. That

is, although we may debate physician-assisted suicide, or euthanasia, ultimately control actually does exist in each individual's realm already: people can choose not to eat, and, more importantly, not to drink. And there is some good data to suggest that in those situations, people die a painless and, as described, a good death, usually within about 15 days. So in some ways, we may look at this debate as narrowing down to whether death occurs nearly instantaneously over a period of hours or over 15 days; and whether or not voluntary cessation of food and drink feels different and from a public health perspective is different ethically from physician-assisted suicide or euthanasia.

In palliative care, there is also the concept of terminal sedation or terminal palliation, where patients whose symptoms are uncontrollable can be completely sedated, essentially made comatose through pain medicines and sedatives, with the expectation that they won't wake from the sedation and will die under sedation because without it they are suffering intolerably.

In short, before we even address this question of physician-assisted suicide and euthanasia, we as patients and as health care consumers need to pay attention to the control that we do have. Control is a huge issue in most of the research looking at patients in the United States who request hastened death.

The second caution I would make in light of Dr. Keizer's discussion is to make really explicit some of the risks involved for patients. One thing we know is that physicians aren't good at making prognoses. And perhaps this is one of the things that went into the dis-continuation of the regulation about terminal illness. Physicians aren't very good at deciding when someone is going to die. We're a little bit better at diagnosing death for patients who have metastatic cancer, but we're essentially horrible at doing it with any other disease. And the majority of Americans don't die of cancer, they die of serious chronic illness. And for heart disease, for end-stage lung disease, for Alzheimer's, physicians are notoriously poor at making prognoses regarding death and are probably not going to get much better. Hence, basing euthanasia on what such prognoses is certainly a risky business.

The most disturbing data concerns people who change their minds about their own deaths. Oregon, as well as Holland, has instituted the regulation that a desire for hastened death or physician-assisted suicide or euthanasia be consistent over time and be durable, unchanging. But what time period could we all agree on? Over a period of two months in one large study, about 10% of patients who were at the end of their life wanted to hasten their death. When they looked at those patients again two months later, it was 10% of patients who wanted to hasten their death, but it wasn't the same 10%. And this is an important fact for all of us to pay attention to, especially when we're looking at the question of durability of the desire for death. So about half the people who had said that they wanted to have hastened death stopped wanting it, and about half of the 10% were people who newly desired it. We know, interestingly, that some percentage of patients will change their mind regardless of what you do, regardless of what treatments you provide to them, but probably three times as many patients will change their mind over time if we address symptoms of despair, perhaps with medicines, perhaps with things other than medicine.

The other tricky matter that I know Dr. Keizer and other clinicians in the room will recognize is that there is a possibility for growth at the end of life, that each day towards the end of life brings perhaps as much or more change and potential for growth as the first days that a baby is born and comes into the world. So that most of us have some stories, either from family or friends or from patients, of people whose perspectives changed from one day to the next. A sunset took on a different meaning when they survived the next day, experienced a chance encounter with someone in the hospital, or in the nursing home, or at

home, received a visit from a long estranged family member. And these possibilities are something that we need to take into account when we're considering hastening a patient's death.

Certainly, the risk to families is present: the guilt. The issue of burden is an interesting one. Although most patients worry about being a burden to their family, most families won't report, to us anyway, that they feel that the patient is a burden to them. We need to think about communication and support in the family relationship in dealing with issues like this.

And, ultimately, the last risk I want to discuss is the risk to the doctor-patient relationship. We know through our experience with managed care that the trust inherent in the patient-physician relationship over a long time is easily broken. The change in the insurance structure, the reimbursement structure, really threatened the trust that patients can have in physicians. As soon as it became possible, under managed care contracts, for physicians to be reimbursed for something other than what was in the patient's best interest, mistrust became a very explicit issue in the doctor-patient relationship. And it's quite clear, based on our experience with Dr. Kevorkian, that it won't take much for physicians to do along the lines of physician-assisted suicide and euthanasia in the United States, to threaten trust much more seriously. Whatever we do we need to pay close attention to how we're going to maintain the sanctity of the doctor-patient relationship, and the advocacy role that physicians can play.

Let me expand this concept and say that euthanasia and physician-assisted suicide are a very small part of a much bigger, and I would say much more important issue. Dr. Keizer also concluded with this: the issue is ultimately palliative care. I think what most Americans have called for is control over their dying, to the extent of being able to avoid their worst fears of dying in pain, of dying in suffocation, of being a burden to their family, of having a death without dignity. Hence our ultimate and primary focus, I think, must be to continue to work toward providing that control and making possible the goals embodied in palliative care: to focus on the patient's comfort, the patient's quality of life.

The statistics from Oregon are interesting for us to consider. About 50% of patients who have end-stage illness and might be considered to be dying say that they want the option of physician-assisted suicide for some later time. As more time passes and palliative care is applied, about 10% of patients seriously consider physician-assisted suicide in Oregon. About 1% of patients in Oregon who are dying actually go on to make the request. So, though, 100% of people die, about 1% of people, at least in Oregon, actually went on to make a request for physician-assisted suicide. And, ultimately, as a result of the regulations and the logistics in Oregon, about .1% of the dying actually achieved death through physician-assisted suicide.

So the question of physician-assisted suicide and euthanasia actually applies to a very small number of patients, one in a thousand. And I would argue that our primary focus needs to be, and especially as we think about this from a public health standpoint, on the 999 other patients who are making decisions perhaps out of desperation, perhaps out of seeing the end of their lives only in a black and white, a die in the ICU or die at the hands of Dr. Kevorkian, kind of perspective. And physicians need to ask themselves how they, as physicians, are going to respond to the desire for hastened death, to the request for hastened death, because that initial plea may, in fact, be a plea of a much grander or deeper or different scale than simply a plea to hasten death. That may be plea for pain relief; it may be a plea for attention to despair. And although I will certainly accept that there are a small percentage of patients, ultimately, who are actively seeking and realistically seeking hastened death itself as a goal, the vast majority of patients are benefited

by attention to the plea for better care through their life, and perhaps to stay within the schema that we have of dying without a physician's assistance or without euthanasia.

Thank you.

PATRICIA BENNER, Ph.D.

My background is that of nursing. I have taken care of patients who are dying, and I too support the notion of really good palliative care. I don't endorse or want anyone to die a tortuous, horrible death while we stand aside, not doing what we can do.

From an ethical point of view, I regret that in the United States we missed the opportunity to change our practices around end of life issues before death became inexpensive or cheap, and care became so expensive; with managed care, suddenly the moral landscape and the backdrop of end-of-life care radically changed. Always before, it had been profitable to keep patients alive for a long time. Now, suddenly it was more profitable if they died sooner.

I have always worried about the kind of discursive spaces we create in care for the dying. I would not like death to be reduced to a mere biological event that can be handled more and more efficiently. It seems to me that does something really terrible to our sense of our responsibility to one another to care for one another. And I have participated in many palliative care deaths where you, Dr. Keizer, might think, 'Well, these are just sort of hidden physician-assisted or nurse-assisted suicides.' I don't think so. I don't think that clarity is what it's cracked up to be. Death itself is ambiguous. People are under the cloud and myth that they are going to choose death or choose to control their death, but, in fact, death always wins. And so how we understand death as a human passage, I think, makes a great death of difference.

I was really chilled by an account by a local Bay Area reporter that came out about the same time that Bill Moyers was doing his big report on death with dignity. You might wonder why we spent so much money on death with dignity in the last 10 years, just as death became the less expensive option. But in this documentary, the journalist kept noticing that it was the wife who was speaking for the husband in desiring a speedy and efficient death. The husband really preferred to linger for awhile, and wasn't at all anxious for the care space to close, leading to immediate death. This example raises the specter of what kind of trust we create within families, and within the spaces where we care for the dying.

How do we remain courageous in providing the good comfort, care, and palliation that people deserve? Even though I want to cut it off from its religious moorings, I love the double-effect theory: as a skilled clinician, I really don't want to be in a position of nurse-assisted suicide or euthanasia, but I do want to be in the position of very skillfully moderating the morphine, so that someone is comfortable, and even the family is comfortable. I know how to do that. And as long as I'm doing that, I'm pretty clear, yes, it's hastening death, but death is coming anyway. But how do we hold open death as a human passage where we close down a biography and a life, and not just a physiological life?

I think there is something seductive and maybe a little unsavory about being in charge and in control of death, and we ought to be cautious about that. In my own practice. I'm very clear that I do not want as a professional to do assisted suicide or euthanasia. But as a private family member it's a very different issue

for me to think about, and I remain ambiguous and agnostic about how I might respond should a loved-one be begging for relief and earlier death. Again, as a nurse, I would not like to have on my list of weighty responsibilities—they're weighty enough as it is—having to confront, once or twice a month, or even once or twice a week, that rather awesome decision. And, as Dr. Rabow has said, I do think the time period is really crucial because people can be thinking really catastrophically one day, and their horizons can open the very next day.

My greatest concern in this age where the gods are mostly dead—not all of them, but most of them—is how we can keep open a respectful discursive space, and how we can change our social contract so that it isn't between autonomous adults only, but rather between people who intermittently need total care at birth and childhood, and then again in our old age. I look toward a space where care itself is deeply valued.

## Open Discussion

DR. KEIZER: Let me make a brief response to these interesting comments.

I work mostly with elderly people in a chronic care facility. This is not a job that is considered very attractive for doctors. I mean, you want to work in the ER, right? That's where you are snatching people away from death all the time, not easing them into it. And in Holland, as in your country I am told, working in a nursing home, looking after Alzheimer patients, is just not very glitzy. If you look after astronauts you can walk in anywhere, but looking after Alzheimer patients it's not one of those jobs that you get people queuing up for.

It's the same in Holland, exactly the same, because in that respect, our society looks towards old age the way anybody in Western society does. I think this is an awful thing, and I do not know any way we can counter it. The training of doctors and nurses is geared to getting people out of trouble. And if they are in trouble and you can't get them out of it, and that is the case in chronic care, then you have a situation where doctors like to say, "There is nothing we can do." This is actually a pretty stupid thing to say of course because a lot of things have to be done then, but still, that is how we are all trained, and again, I don't know to counter it.

DR. RABOW: Well, again, I would point out a couple of things. One is that we should be wary about making a stark dichotomy between snatching people away from death or easing them into it. There is clearly, I think, a long tradition and a happily a growing one, of really helping people through what life brings them. This brings about a different kind of doctor-patient relationship. It's not the strong paternalistic physician making decisions, but rather a shared decision-making partnership. And there is some hope in current training practices in the United States, which is really the only country I know about, where end of life care training has actually become a requirement for medical schools and a requirement for continuing medical education in at least six states, including California, for practicing physicians.

So there is absolutely, I think, some reaction to the idea of a horrible ICU death where people are being tortured by overly aggressive intensivist curative efforts and we are moving toward a stronger focus on the aggressive attempts of palliative care. People are starting to see the falsity of that comment that there's nothing more we can do. Rather, we can fill out the rest of the sentence—there's nothing more we can do cure this cancer, or reverse what is going on with you in terms of your dying, but there is everything that we can do to try and provide comfort, even guidance, through this time.

AUDIENCE: What is the answer—if it's not an advanced directive? What do you think the answer to the question is?

DR. KEIZER: I don't think there is an answer. In the case of dementia, for example, if you can ask for

death consistently, then you are not demented. I sympathize with people who say, 'I do not want to end up in that way.' But dementia is like the falling of the evening—you don't know what time the evening has fallen. Dementia is like a morning fog; it just creeps up on you, and there is no time where you can say, 'Now I am demented. Now I would like to die.' The mental makeup of a person entering into dementia is such that, certainly in the initial stages, they will fight it and deny it. And once they're deep into the fog, then they can't ask for death anymore, not in a consistent manner.

And you can't just write down something specific, like 'If I do not anymore recognize my own children, then I want to be killed.' In Holland, there is no one geriatrician who is willing to even consider that possibility, because if you recognize the hospital doc or have a good relationship with your nurses who look after you, even if you don't recognize your own kids, who would be willing to kill you? In short, the physician can't just put the advanced directives under the patient's pillow and hope that they wake up dead in the morning. It doesn't work that way. You have to really kill somebody. And so you would have to kill somebody who might ask you as you hand over the barbiturates, 'What's all this about?' And you would say, 'Well, this is your final drink.' And they would say, 'I don't want to die.' 'Yes, but 30 years ago, you said you would.'

So I just can't see how we can solve that. It's like aging. You can say, 'I don't want to become old.' But the only answer, preventive suicide, is simply silly: you're not going to kill yourself because one day you might become old.

AUDIENCE: I wonder if Dr. Keizer could tell us more about barbiturates. It's extremely difficult to get barbiturates in this country, much more difficult I expect than in the Netherlands.

DR. KEIZER: I don't think you're right there, because barbiturates are very difficult to obtain in Holland without prescription. And a doctor won't prescribe them, because the medical indication to prescribe barbiturates is epilepsy, for which we now use other drugs. If I were to prescribe barbiturate for you because you say you don't sleep very well, my colleagues would frown and say, 'What are you doing?' Barbiturates have been sort of forced into the closet. It's awful, but it's true.

AUDIENCE: I have a comment and a question. First, although I found Bert Keizer's story of his work sad, I also found the accounts that we've just heard rather frightening. Now that may be because I'm American and I know how American hospitals work, and I know exactly what the factors are that Bert and Patricia Benner raised about money, and about power, and about family involvement or lack of involvement. But, also, somewhere in there I detect a hidden form of—for lack of a better word—paternalism. I don't say that accusingly. I think it's so hidden it's not willful, it's not nasty; but there is the notion that the doctor has a concept that life is good and needs to be prolonged. All the speakers suggest that change and growth are possible at the end of life and that change and growth are positive. And you're saying that maybe at the end of life, just as at the beginning, we need to learn to be dependent. This presumes that existence, even if dependent, is positive.

And I find that frightening because having been in the hospital last year with a friend who died over a three-week period I saw how the medical profession operated, and I saw the lack of individual contact between the doctor and the patient. That's just how death frequently works in hospitals here. Whereas, what I hear in Bert Keizer's story is some kind of knowledge of the patient, and allowing that knowledge to be part of the interaction. In other words, death is not the only event that is happening, and there are many other interactions going on between the geriatric care doctor and the terminal patient. Perhaps being a doctor is like being a teacher. That is, we all go to school, and once in our lifetime we find a teacher who really gets to us and teaches us something in the way they're we're capable of learning. This is not a life or death matter in the same way as getting a good doctor, but your chances of getting that one doctor that can reach you that way, or feel for you that way, or understand which of the issues you find important—that you might not think growth at the end is important or that dependency is positive. The chance of finding a doctor who will grant you that integrity and that difference is small, especially given the current American medical system.

PATRICIA BENNER: I agree. I'm scared to death to die in an American hospital, and I wouldn't let anyone I care for die there alone, without my being with them. But interestingly, I think you misunderstand the dependency side. None of us wants to be dependent, but my emphasis was the willingness to care for the dependent one, the willingness to make that dependency less onerous. I was speaking from the caregiver's side.

AUDIENCE: Yes. And there are also the financial reasons that make the situation harder and harder.

PATRICIA BENNER: Dependency is becoming more onerous to us because the social acceptance, and the availability of skill and knowledge to provide care are all diminishing. I think dependency is a bitter pill for many adults. Even children don't like it a whole lot. So I didn't have any growth in mind for the dependent one.

AUDIENCE: Now, my question: why can't this problem of a doctor's having to confront the legal system after the death be resolved by reversing the order? Why can't the doctor get the patient's request in writing, get the second opinion from the independent colleague, wait the necessary duration, present all this material to whatever court decides it, and have the decision made before the patient's death?

DR. KEIZER: The answer is legal. Euthanasia is still against the law in Holland, and you cannot ask the law to allow a transgression. Afterwards they can say, 'Oh, well, this was an exceptional case.' And that is the way it has been construed, because it is still against the law in Holland to take someone's life.

PATRICIA BENNER: But, also, the timing of that is totally untenable. If someone is suffering unbearably and wants assistance, to wait a couple of months until the courts deal with it could be impossible.

AUDIENCE: But then what is the duration requirement?

DR. KEIZER: You can't specify it. If I meet a patient on Monday, and on Tuesday I hand her an overdose, everybody will say this cannot be correct because there cannot be time for the doctor-patient relationship to develop. You can't establish that relationship in 36 hours. If I had known a patient for two weeks, I might get away with it. But I would never think of meeting a patient on Monday and being involved in euthanasia on Tuesday. That makes no sense at all.

AUDIENCE: What is the duration of time from death until the final disposition?

DR. KEIZER: It takes about six weeks. I want to emphasize that in Holland is still very exceptional.

DR. RABOW: It's clear that most people in the room agree that there is ample evidence that death in the United States can be a horrible affair, especially in hospitals. I mean, there's no question about that.

But I do want to clarify this issue about growth at the end of life. It is absolutely not something that I think physicians should be prescribing to people or forcing people to seek out. I only observe that this is possible for some people, that some people come to label their diagnosis of cancer as the best thing that ever happened to them, because of the existential changes they experience and the shift in perspective that dying may bring. So I clearly want to make that one response. I do not believe that physicians should be regulating that people grow. 'Grow! You're dying. Appreciate it.' Absolutely not.

The other point is, though, that physicians can be of service to patients, can meet patients where they are, and develop a connection with the patient that clarifies life's meaning for the patient and what her/his goals are. A focus on understanding a plea or a request for physician-assisted suicide is a good place to start. This is not to say I believe or I don't believe in doing that, or it's legal or it's not legal, but really to try to understand what the request means. What does life mean to you? What is a life worth living? From where does your desire for hastened death come? I think that this is not just an opportunity for physicians and patients, but actually a responsibility for physicians. We not focused on adequately on this in training physicians, because as you point out, the number of physicians who might respond in that way is still low.

PATRICIA BENNER: I think I can make my argument just a little clearer. From my experience as a practitioner, I was articulating my faith in situated decision-making, where you know the patient and the family, versus abstract formal rules that can be applied even capriciously. We have too few good practitioners, but there are still good people out there.

AUDIENCE: I'd like to make one more quick point that may be related to the point about changing one's mind. I have noted from personal experience with someone who was dying in the hospital that the nurses tended to say things like, "You have to be positive." But I wonder if this was almost more for the nurse's benefit than the patient's.

PATRICIA BENNER: Yes. It makes the nurse feel better.

AUDIENCE: I'm a psychologist. I realize that there are different levels of functioning, and it doesn't surprise me that people change their minds on issues relating to death. Personally, I would like to see a situation, where I could specify ahead of time, and say, "Well, I want this meaning to prevail, because I know the other one is going to surface and I don't want the other one to prevail." I'd like someone to respond to that.

My other point is a minor technical thing. As for palliative care, it's my understanding that in a lot of cases palliative care is less expensive than heavy intervention, because there are fewer CAT scans, PET scans, expensive chemical ingredients, and so on. This suggests that the decision to put a patient under palliate care may be economic.

PATRICIA BENNER: That's exactly the issue now.

In the past, intervention was profitable, and so it was often hard to get the intervention stopped. That would have been a great time to make a change toward palliative care. Now, death or palliative care is much less expensive, and continued intervention is very expensive. We have a switch in the moral landscape.

DR. RABOW: Just to add to that, and then to address the other comment, it's still probably unclear whether or not good palliative care is more or less expensive. There are conflicting studies. Palliative care can be as aggressive and require as much or more intervention, and, certainly more time. Time is very expensive in terms of intervention. Interestingly enough, there's some early data out to suggest that palliative care actually prolongs life. This is a common experience in hospice, where when people come to perhaps some sense of emotional or existential peace— at the very least when they have their pain and nausea treated—they're able to live a little bit longer. So some of the dichotomies that we have about time and money factors may not really play out, and we're ultimately left with the moral, ethical, and public health issues.

In terms of the question of which me I want believed or listened to, it's an important point. Everyone is conscious of the need for people to be clear and not depressed when they're making decisions. We also have to agree that people develop in real ways too, so that what I wanted at twenty I might not want at sixty. My mom once said, "when I turn fifty, Put me in a Jaguar and send me off the edge of the cliff," but when she turned fifty and we reminded her of that request, she said, 'Oh, I've now seen that there's actually more meaning in life than I thought when I was thirty."

AUDIENCE: Thanks for this great session. As usual more questions come up than answers, and I have two, at least. First off, Dr. Kaiser's story of Mr. Johnson reminded me of a former patient of mine who was Dutch, who was dying of congestive heart failure, who had a no-nonsense attitude about life and death, who, if it had been available, would surely have requested and used assisted suicide, and with assisted suicide not a possibility, wanted the best palliative care hospitals. And I imagine that she and you, and maybe a great majority of the people in the Netherlands, would, if given the choice, want to live in a country that had both the best palliative care at the end of life and the possibility of euthanasia. But given a non-European influx of people into the Netherlands, I wonder if you see changing attitudes toward death and

dying, if the acceptance of euthanasia was in part the product of a somewhat monolithic culture. Here, we have such broad and culturally diverse attitudes, often based on religious concerns, that I think we would never reach agreement.

In short, can you comment on the cultural aspects of the decision in the Netherlands to allow euthanasia to go forward; and do you think that the influx of people from outside northern Europe will change attitudes.

Also, I wonder where terminal sedation fits into all of this. Terminal sedation, which is accepted here in the United States, seems to many people to be very close to euthanasia.

DR. KEIZER: In Holland we say that terminal sedation is euthanasia the British way. "We're doing it, but please don't talk about it."

PATRICIA BENNER: I like the ambiguity because I trust it to be quite situated, and sometimes I think it's absolutely a good and right thing.

DR. RABOW: I want to say that terminal sedation does have a place in the foundation of palliative care as practiced now in the United States, but I think it's happening mainly in cases of intolerable physical symptoms. Deciding how to respond to despair and existential suffering is not the same as making decisions associated with severe, unrelenting, intolerable physical pain. The concept of terminal sedation is giving a medication to treat a symptom, even if you need to give so much that the patient is sedated completely. But this is not the answer for existential suffering, where we might think rather of voluntary cessation of food and fluid.

AUDIENCE: So if someone is just feeling hopeless and helpless, and decides to stop food and nutrition even though they aren't imminently dying the physician might say, "Fine, you're right, stop..." and then treat the symptoms of withdrawal of nutrition. That's okay?

DR. RABOW: It's most states it's relatively okay. In some states, stopping the feeding tube require a little more burden of proof, but in most states you can get by with not forcing feeding tubes on patients who refuse to eat.

DR. KEIZER: We're shuffling around euphemisms, right? We're talking about palliative sedation, because terminal sedation immediately turned into terminating sedation. We make a patient go to sleep without their ever waking up again, and we don't give them liquids or food, and we still maintain that we do not intend them to die. Someone compared that to throwing somebody out of a window on the ninth floor to give them the experience of flying. It will be all right until they hit bottom. You never intended the person to fall. It was all about flight, but they unfortunately hit the pavement.

So you can say with terminal sedation, "I do not intend this person to die. I just don't want them to

have to live through their symptoms.” There is a lot of ambiguity here, and the physician can still say, “I am not killing you.” This is a very important feeling that’s in all of us.

I don’t want to sound sort of patronizing, but this is more difficult to understand if you have never attended a death bed. I can put somebody on a schema of morphine and I know that because of my morphine they won’t eat or drink, and they will die after three or four days. Someone could then say to me, “Well, what’s the difference? You might as well kill them then.” But that is a silly remark because to me, psychologically, there is a huge difference. We can’t deal with concepts like terminal sedation that way. I go along with what Patricia says: we find a way to deal with things that we find. As we sit here it all sounds pretty clear that we are talking about killing a person; and yet I would defend it as not the case. No, I don’t experience it as killing a person, not at all.

AUDIENCE: Do you want to speak to the cultural diversity question?

DR. KEIZER: I was trying to avoid that question. Dutch people don’t look abroad, and say, “What’s the matter with you people?” But everybody looks at us and says, “What’s the matter with you Dutch people?” One thing is that we are a relatively stable society. And medicine as practiced in Holland is so different from the way it’s being practiced in the States. I work as a doctor and people are dying around me quite often. I have no insurance against anything. Nobody ever sues me. There is a judicial structure in the Netherlands, and as a doctor you can be judged on what you are doing, but there’s never any money involved. I’ve appeared before courts because offspring had thought I had killed their parents. Yes, that’s the way it happens. But generally the level of trust in Holland between doctors and patients is much higher than in the States. I don’t know what happened to you, but it did not happen to us. Of course it’s so difficult to look at another culture, and then try to understand what’s going on there.

AUDIENCE: And the attitudes of the immigrants?

DR. KEIZER: They have no political clout, no influence on this debate. But they really believe in medicine the way it’s advertised, and they really do believe that what doctors promise can be delivered. So they will never accept anything in the way of euthanasia, or palliative care, or artificial hydration, or respiration, etc. This creates a huge problem. There are two kinds of death beds, one for immigrants and one for locals. The locals are quite easy in saying, “Come on, let’s finish. I mean, it’s okay. Let Mother go.” The immigrants are—I know this sounds terrible—so much more naïve in their expectations of what medicine can do. If you suggest as a doctor, “I think we’d better not send Mother to the hospital,” they will look at me and say, “What are you saying?” Their preference is for somebody to die a lingering death on artificial respiration. For them that is a more respectable way of going out than what you and I might prefer.

DR. RABOW: Can I just add one thing just on this point. There is data in the United States that African Americans, in particular, and other ethnic or racial minorities make different palliative care decisions than ethnic majority white Caucasians do. And, typically, it’s along this line of insisting on more

interventional care, aggressive care, and less palliative care. Although it's not exactly clear why that is, one of the issues is trust in the doctor-patient relationship, and the long history of experimentation, mistrust, inappropriate behavior, and experimentation like the Tuskegee case that cause African Americans in this country to have a different relationship with physicians, regardless of the physician's ethnicity.

AUDIENCE: I've just been thinking about this idea that you have to be able to ask for death over and over again. If you're asking for death because you're depressed, and that depression can't be treated for some reason, and your dying is not imminent but you're tortured by thoughts of wanting to die, where does this all fit into what we're talking about today?

Dr. Keizer: Well, in Holland, psychiatrists are really sort of allergic to euthanasia, because obviously the requests in that context are tainted. A psychiatrist might think, "If I give one the overdose, they'll be queuing up." And who is going to sift the real questions from the sick questions? That's a very difficult problem. Fortunately for me, the kind of people I deal with are usually at the end of life, like the patient I described, facing pretty clear-cut catastrophes. If I were talking to a young person who is depressed, and incurably depressed, I don't know what I'd say. I have never encountered that situation.

In Holland, there was one case of, I think, a 42-year-old woman. She had lost two children through suicide, and she was not ill at all. She was depressed or sorrowful; we are still fighting about that. She asked for death and she was granted euthanasia, or physician-assisted suicide, I should say. And the high court—I'm assuming that this went up and up and up—sanctioned what the doctor did. But in the country there was controversy because it was felt that depression is often abused as a concept. I don't know what the answer is, but in Holland it certainly is not usual or likely, even, that the depressed person would get euthanasia.

DR. RABOW: I was just going to add that the data in the United States is somewhat mixed about what proportion of patients who request hastened death have depression, and whether or not it's an independent risk factor for their request. But your point about a kind of medical model of depression, that depression is a disease that causing suffering, just as esophageal cancer is a disease that can cause suffering, is a very relevant one, and becomes very difficult in Oregon, as in Holland. Psychologists/psychiatrists are required to make an assessment about whether or not someone is depressed. And that becomes, right or wrong, in some individual situations a reason not to allow physician-assisted suicide here.

The diagnosis, though, of depression at the end of life in particular is extraordinarily difficult. Some of the most recent work is trying to figure out how we can accomplish that assessment, which is difficult because many of the symptomatology of depression look like end stage disease—people are tired, listless, low energy, difficulty with sleeping and eating. And so we end up having to focus on much more difficult concepts to identify and assess the more psychological elements, a sense of self-reproach, a sense of failure, and it's a very difficult issue.

AUDIENCE: I like the idea of ambiguity, but are the alternatives named in a conversation with the

patient or with the patient's family? And once something is named is it still ambiguous?

DR. RABOW: Most physicians practice the principle of secondary effect or double effect, which is that something is considered ethically acceptable if the primary goal is acceptable, even if there's a secondary effect that is known and knowable but unintended. The request might be, "Can you please treat my pain, and I want it treated even if it means putting me into a coma. And if the pain is not going to go away, keep me in a coma to keep me out of pain," Then a discussion can happen, and should, happen, with the physician and the patient, or more often it's the family or surrogate decision-makers. But from an ethical perspective, this discussion is dependent on the concept that the primary goal is symptom relief, with a known secondary effect of, 'Well, you know, if you're in a coma and we don't give you artificial nutrition or hydration, the secondary known and expected side effect will be that you will dehydrate and die of dehydration.'

PATRICIA BENNER: I want to point out that terminal sedation is rather rare. It's not very common because there are many other steps to palliative care that usually work. So, again, we are talking about a very situated decision-making process where you know the patient, the family, and the physiological condition.

DR. KEIZER: I would say the great secret of the British hospice movement is that morphine is just raining down from the ceiling. That is their secret. Morphine has all kinds of effects, and one effect is never mentioned. We underestimate this effect of opiates. If you put a patient on a morphine schema, that's not a bad proposition. It's just drifting off the planet on a very soft couch. And no one says, "And now we are going to sedate you." It doesn't work like that. You meet symptoms, and you fight against the symptoms. And in the end, most of your patients will be sedated before they die. And it's very rare that you would make an appointment: "at 10 a.m. tomorrow we will start sedating you." But it does happen, particularly in Belgium. They don't like euthanasia, but what they are doing seems like euthanasia to me.

AUDIENCE: The last time we had a study of really natural death, with was also a rather not very good study... where vast numbers of patients died in a coma anyway.

AUDIENCE: Is there a study of really natural death

AUDIENCE: Well, we haven't done that for a long time, dying naturally. I mean, it's hard to study.

PATRICIA BENNER: And there's no classification of natural death anymore.

AUDIENCE: The panelists talked about palliative care as an alternative to physician-assisted suicide or euthanasia, but the cases that we heard about from Dr. Keizer were not cases in which palliation was relevant. Your 92-year-old man wasn't in palliative care, and the cancer patient whom you mentioned might have been in palliative care sometime, but wasn't. Assuming these cases are prototypical, one could see they are relevant to your schema. But there be some disjuncture between these cases and others. I wonder

if you could comment on that.

DR. RABOW: I guess my brief comment would be that I tend to focus on what physicians can do, and nurses may focus on what nurses can do. But one of the primary principles about palliative care is not something that we've talked much about in the room yet today. This is the idea of interdisciplinary care, that there are all sorts of people involved in attending to all the domains of who a person might be dying. Pain is not the only issue, although it's one that Americans probably fear the most. But existential angst, spiritual crisis, are also part of what palliative care may hope to address.

AUDIENCE: Right. Well, as Dr. Keizer described the elderly woman with the broken hip, she was not in despair, existential or otherwise. I mean, this seemed like a case of someone who says, 'Look, I don't want to be dependent.' And then she left in very good cheer.

PATRICIA BENNER: It was decidedly a Dutch possibility of death. You couldn't do that in our current system in the U.S.

DR. RABOW: Well, I would say that it's not just a question of whether or not assisted death exists; it's a question of whether or not it's a physician's responsibility to facilitate it. And that, I think, ultimately comes down to both a practical and philosophical issue, when you ask physicians whether they would perform euthanasia or physician-assisted death if it were legal in the United States, about a third say that they would. That means two-thirds of physicians say that they won't.

AUDIENCE: What percentage of Dutch doctors won't perform euthanasia?

DR. KEIZER: If you asked them on the street, I think about 80% will say, "It's okay by me." But when it comes down to, in a sense, delivering the goods, I think about 60% would do it and about 40% would refuse.

AUDIENCE: I think it's similar here. In the abstract, 60% of physicians would probably agree, but the actuality may be different.

DR. RABOW: There is a practical matter here. If patients want it, and our society agrees to its legality, who is going to do it, and why? Obviously, physicians are a reasonable choice since we know how to administer doses, and we're used to giving IV's, etc. But the question remains of how the physicians and patients characterize the role and responsibilities and opportunities of the physician; and this is where we come back to the trust issue.

DR. KEIZER: But do you think that physician assisted death doesn't happen in the States?

DR. RABOW: Oh, of course not. I know that it happens, and I believe all the data that suggests that it does. As a matter of fact, if you look across the Bay in San Francisco in the research that was done before highly active retroviral treatment for HIV, probably more than 50% of clinicians reported physician or nursing-assisted suicide or euthanasia. So I know that it happens all the time. But that's not really the

issue that I'm focused on. It's really more about making prospective choices about how we're going to understand our roles as physicians or health care clinicians at large.

DR. KEIZER: But do you think that a suicide pill should be obtainable, then?

DR. RABOW: I think that we could have a larger discussion about prescription medications, in general, but I have to say I'm more focused on this issue of voluntary cessation of food and fluids, because I think medications have an invariable association with health care and with physicians and nurses, and I think we have to be wary about how we use medications for that reason. Whereas, when the issue is control, where I believe it often is—and most literature supports that—there's nothing more in people's control than something that they don't have to buy, they don't have to get a prescription for, they don't have to get from Canada. They actually have the control within their own very being. When we approach this issue with control as the goal, we can ask if there are there ways of achieving control that are effective, safe, and available? This broadens the discussion, and takes it away from assisted anything, although obviously there are conditions where people might want to have someone else remove the feeding tube. Lou Gehrig Disease or ALS might be examples of that.

AUDIENCE: You repeatedly talked about dying through refusing food and water; but isn't this a painful death?

DR. KEIZER: No. If your doctor says, 'Okay, don't drink and eat anymore,' you will not get the 'desert thirst.' This doesn't happen, certainly not if you're elderly, because your thirst impulse is not quite so fierce. So it's not a horrible way to go, but a doctor or nurse must be around to supply you with the morphine to make it bearable, and it's not so easy to find that person.

DR. RABOW: In fact, physiologically, it's interesting that the physiology of starvation causes something called ketosis, which actually gives people a mild sense of euphoria. And so when we look at starvation protestors, for instance, they generally don't report being uncomfortable. There often is some dry mouth, which is not quite the same as thirst. That can be relieved with some topical moisture. In general, dehydration is a very good way to die. But it may be difficult for the family or other caretakers because most of us express our love through providing food and water to loved ones. You can't have someone coming in and saying, "Here, I made you this nice bundt cake." A little carbohydrate is going to reverse the whole ketosis, and the patient goes from being euphoric to having a nice piece of bundt cake.

AUDIENCE: Ketosis is a little antidepressant. Morphine actually is a little antidepressant, even though we don't prescribe it for that. But standard antidepressant therapy, other than electroshock therapy, requires at least a month before you can say it's not working. And according to some good studies it requires about two months. But aren't we talking here about using starvation or morphine to treat depression.

Moderator: Unfortunately our time has run out and we are going to have to stop here. Our thanks to

all our panelists for a wonderful discussion.

# Medicine and Humanities: [E]merging Definitions

Roundtable Discussion

March 3, 2004



## Medicine and Humanities:[E]merging Definitions Roundtable Discussion

ELIZABETH DUNGAN: I graduated with a Ph.D. in art history, but my background prior to that was in medicine. I have been teaching a class with Guy Micco on Pain and Suffering. In my dissertation I looked at the intersection between contemporary art and medical practice, medical imagery. I'm very interested in thinking about how we might become self-conscious around our behaviors of looking. Like Jodi Halpern and her work that integrates a philosophical model around empathy and compassion, I'm interested in how we become self-conscious around some of those behaviors of looking and identifying what those images are; how this might help us with thinking about death and dying, pain and suffering, aging, all of these things that we've been working on together.

THOMAS LAQUEUR: I try not to think about the topic. What's wrong with denial? I'm Director of the Townsend Center. And I'm working on a book called *The Dead Among the Living*, which is about memorials and cemeteries and the like. But I've been writing about death and old age for a long time. And my most ongoing engagement, I suppose, is arguing with Guy, who believes that reading literature will make you a better doctor.

JODI HALPERN: The topic today is humanities and medicine, and some of my interests have to do with death, but some have to do with life. I'm a psychiatrist and a philosopher. A unifying theme in my work is the emotional imagination and how emotional states affect how we conceive of our own and other people's possibilities. Beth kindly mentioned my work on empathy. I wrote a book on empathy, which had a lot to do with how one person imagines and grasps another person's suffering, or completely fails to see another as human. And more recently, I've been thinking a lot about catastrophic thinking, interestingly, in situations where people are facing life or death choices. How our states of mind can close down our lives even before our lives are closed down is something I'm very interested in, and it seems to me that that's the part that relates to death and dying.

Other parts of my work don't. Because I'm a psychotherapist as well, I wrote a controversial paper that came out last spring called 'Overcoming Denial—Facing the Harm that Psychotherapists Can Do by Writing About Their Patients.' And so I've become a kind of figurehead in the bioethics movement now. I've always cared deeply about the arts and humanities, and been respectful of their place—but I realize that I really need a way of thinking about creativity and narrative as a way of conveying cases. I've pretty much convinced myself that psychotherapists should not write about their own patients as medicalized cases, that this violates the language you use in psychotherapy. The kind of empathic discourse is, I think, utterly at odds with the kind of description case presentation, and when patients then read about themselves written that way by their psychotherapists I think it's really an undoing. It may be that people should be writing in very different ways, or conveying things in very different ways. And that's what I would love to

hear somebody help me with today.

ORAN FRANCO: I'm a first-year medical student in the Joint Medical Program here with UCSF. My interest is pretty broad at this point. I'm just looking forward to hearing different perspectives on bringing humanities into medicine, something I can take with me.

GUY MICCO: Tina has asked several of us to make comments, and I have a sense that we don't have shy commentators here. I'll start and then we'll go on from there.

'Consider modern medicine a practical technology that is highly developed scientifically. The general presupposition of the medical enterprise is stated trivially in the assertion that medical science has the task of maintaining life as such and of diminishing suffering as such to the greatest possible degree. Yet, this is problematical. Whether life is worthwhile living, and when, are questions not asked by medicine. Natural science gives us an answer to the question of what we must do if we wish to master life technically. It leaves quite aside whether we should and do wish to master life technically, and whether it makes ultimate sense to do so.'

Now, I wish I had written that, but I didn't. Eighty-five years ago, one of you, at least, should know whom—Max Weber. Not me. But still pertinent, I think, today.

A movement to include—some would say, bring back—the humanities into medical training has been gaining steam for the last 35 or more years. This particular movement that I'm thinking of began in the late 60's, with what some physicians thought was the beginning of a takeover of clinical medicine by a technological revolution. If you listen to Weber, this happened much earlier. The intensive care unit, however, of the 60's, cardiac monitoring, invasive procedures, heroic surgeries, were the lures to what Ed Pellegrino, one of the founders of this movement of medical humanities and still a leader in it, termed 'technicism.' And the patient was being forgotten.

The 'humanities,' in quotes, were seen, simplistically, perhaps, to be the answer to how to put the patient or the person back into the picture. As one other pioneer in the field, Eric Cassell, wrote in 1980, 'If medicine dealt with the body alone, if what afflicted the sick person acted on the body and only the body, and if it were possible to intervene in the illness without interventions taking place in the person who has the illness, then...' to paraphrase him, fine.

But that's not the case. Unfortunately, patients don't just bring in their organs to medical practitioners and leave them off for the lube job or steam cleaning. People come to their physician with all their fears, hopes, expectations, fantasies, and other psychological stuff of personhood in tow. The premise of what has been called the medical humanities, is that all of this stuff, sometimes called psycho-social issues, is better taught by literature and other humanities than by the standard medical curriculum. And this is a major part of what I hope we get to talk about today.

Here's what Robert Coles has to say concerning his encounters with William Carlos Williams, whom he credits with getting him into and through medical school. 'What Williams did over and over was to suggest books I ought to read—Chekhov, Camus, Kafka—not to mention some of his own stories. He urged me to read *Aerosmith* again. He reminded me repeatedly how much Dostoevsky and Tolstoy had to say about illness and its vicissitudes and, of course, Thomas Mann. As I responded, I found the pleasures a reader obtains from a good writer, but I was also prompted toward ethical reflection by novelists, poets, who had a marvelous sense of life's continuing mystery, the ambiguities and ironies which never stop confronting us.'

And here I wanted to add, parenthetically, that if it weren't for Albert Camus' *The Plague*, I wouldn't perhaps be a better doctor, but I wouldn't be a doctor at all.

Coles goes on to point out, 'That while medical students, of course, require a mastery of biological factuality [as he calls it] they also need a chance to ask those haunting moral and philosophical questions that George Eliot, for instance, in *Middlemarch* keeps posing. What is the meaning of life we doctors so constantly try to protect, and how ought that life be lived, with what ideals and aspirations, with what accomplishments, adjustments, compromises in the face of this world's constantly pressing opportunities, frustrations, and obstacles? Mysteries, ambiguity, irony, moral questions, meaning, aspirations, compromises—these are words which physicians-in-training become familiar with through the standard curriculum of biological and clinical sciences.'

At a recent humanities and medicine conference, in a breakout group on close reading of poetry, a conferee suddenly exclaimed with delight, 'I read a lot, mainly medical literature. This is the first time in years I can remember seeing a question mark placed at the end of a sentence.' In a paper titled, 'Humanities and Medical Education, Some Contributions,' published in 1990 in *The Journal of Medicine and Philosophy*, a professor a humanities at Penn State University College of Medicine at Hershey, discussed what he called several qualities of mind that are very important to medicine, and which are distinctively contributed to by humanities in medical education. They are critical abilities, flexibility of perspective, non-dogmatism, ethical values, empathy and self-knowledge—too much to review here, too much for the standard medical curriculum to bear up to, certainly.

In a recent essay in *Threepenny Review* titled, 'Tales of Empathy,' Bert Keizer—not to pick on Dr. Keizer but he is here and he did write it—states, 'One of the most enduring fictions about fiction is the notion that it will mellow people's hearts, or rather, doctors hearts. This mellowing would ultimately benefit the patient who would be looked after in a more caring manner if only doctors read more fiction. A sub-specialist colleague of mine came up to me after what could be called the medical humanities grand rounds at our local hospital and said, in effect—he didn't quite say it this way, but this is how I read it—he said, 'You like to read Shakespeare, I like to go sailing. Who is the better doctor for it?'

So the lines, if there are lines to be drawn, have been drawn, at least in this particular part of our conversation. I know that several others here will take this in far different directions; I think of Nancy, in particular. But I've moved into a very small venue, that of the doctor and patient. Nancy brings it out into a much larger purview. But there are my comments.

DR. KEIZER: I would just answer the diagnosis. I look forward to your therapy. An important cost, I think, of the overestimation of medicine and what it can achieve lies in a misconception of science. Wittgenstein said, 'We feel that even when all possible scientific questions have been answered, the problems of life remain completely untouched.' I think what he means is this: Around suffering there is always the question *why*. So when a patient asks, 'Why am I to die?' and the doctor responds with a lengthy disquisition on the insufficiency of her organs, the leak in her mitral valve, the accumulation of fluids in the lungs, the patient will interrupt all this physiological language and will ask, 'Well, never mind all that. Why me?' And this is the point when a doctor breaks off and holds her tongue, ideally, because she realizes the difference between the existential and the physiological question.

Usually, nothing of all this happens, of course. The patient is dismissed, the 'why me?' question is buried under a deluge of diagnostic moves, the sadness and understanding being that a blood test, an x-ray, a scan can never tell us anything about why we are here. Since God left the premises, I think, somewhere in the 19th century, we have been lumbered with a certain ignorance about the meaning of life. And it seems to me that this ignorance is eagerly buried underneath a pile of tests, none of which can show us why we suffer.

Why does it matter? It matters because it hurts. It hurts when you are faced by a chemistry offered as an explanation while you are trying to digest your suffering, religious, metaphysical, or psychological. The doctor is the man or the woman who succeeds not so much in curing a disease, as in explaining the disease in such terms as to make it credible, palatable, I would say, physiologically, digestible. And my question would be, in what sense can the humanities be helpful here?

SANDRA GILBERT: Well, I'm rather ill-equipped for this. I wrote a few notes to myself before I came here. I have just finished a chapter, which is written from a kind of literary perspective, a readerly perspective, but it's also what we might call a cultural studies perspective. Anyway, the chapter is called 'Technologies of Dying,' which has as its precursor in this particular section of my book a chapter called 'Technologies of Death.' That one is about, obviously, 20th century technologies of killing.

And these are some thoughts that I had as I went through the process of wondering what I could contribute here. For me, I'd have to say the relationship between medicine and the humanities is compelling, or might be, because both the scientific and the healing project of medicine, and the intellectual project or set of projects that we call the humanities, are alike in being interpretive enterprises. They are at least efforts at interpreting the world, and doing so through narratives, through language, and the analysis of language and narratives. And, obviously, medicine also analyses what we call hard science. I'm not denying that there are actual chemicals and other things that doctors look at.

In my own work on what the poet Wallace Stevens called 'modern death,' and what he called in an even more memorable phrase, 'inventions of farewell,' those strategies through which we mourn, I've had to think a lot about how to interpret medical scenes and narratives, as well as the linguistic practices of doctors, patients, and writers who represent doctors and patients. I'll just give you three examples of the

kinds of things that I've been reading. This may all be just old hat to everybody here.

One passage that I talk about at the beginning of my chapter is drawn from a book that the film critic Molly Haskell published in the 1980's about her husband, Andrew Sarasis', near death. She describes the ICU. Just the language in which she describes the ICU was of great interest to me. She describes it as 'like an airship suspended in space, with only the whirring and clicking of machines surrounding mummy-like patients, who are lined up side-by-side with tubes of the most expensive life-saving machinery in the world reaching like tentacles into every orifice, their faces unrecognizable as to sex and age. They weren't humans, but cyborgs, half man, half machine, new arrivals on display from the planet of Near Death.' This is a literary passage that I try to analyze, but also try to analyze in terms of what it means, culturally. This is to talk about, specifically, the gleaning of the ICU as almost a kind of text that one could analyze.

Then in another chapter, I talk about Reynold Price's description of what he calls 'an excruciating series of neurological tests. This is a chapter about the hospital as a space that we inhabit. Price talks about his growing sense of being consumed by a single 'live, idiot creature, concealed throughout this enormous building. The creation had just one blank eye of the keenest focus, and not one atom of self-awareness of even remorse at its endlessly accumulating knowledge, its power over the building's inhabitants, sick and well, and its impotence or refusal to help them.' I try to think about what that means, for physicians as well as for patients.

I end up talking to myself about the hospital as a sort of uncanny space, a defamiliarized space. The term 'hospital,' as you know, comes from hospice, and in this sense a patient is a sort of quasi guest in a hospital. What does it mean to be a guest in this place that like motels and hotels provides you with all of the furniture of home? But it's all bizarre. Like tables that go up and down, chairs that go up and down, lights that look through you, walls that are curtains instead of really being walls—there's just a sort of whole set where everybody wears the same garment, instead of the kind of garments that you would wear at home. And the garments expose you. You're stripped. A lot of poets have written about this, but I try to meditate on it as well.

And, finally, on the issue of doctors and how they treat patients, I want to quote one more passage because I think it's a brilliant example of a linguistic analysis. Maybe you all know this. This is a passage by the poet Alan Shapiro, who wrote a wonderful memoir called 'A Vigil,' about his sister's death. And for those who haven't read it, I recommend it as one of the best memoirs of this sort that I've ever read. The sister was dying of metastatic breast cancer. Shapiro talked about her doctors and he says, 'She came to view her doctor as not just her potential savior, but also her potential judge. When she was doing well, meaning when doing well, meaning when she responded well to the treatment he prescribed he bolstered her self-esteem by saying he was proud of her, she was his best patient, she was his favorite patient. But if he were the benevolent deity when she was doing well, responding to his treatment, he became the Deus Absconditus when the cancer had metastasized and it was clear that she was going to die. Beth, toward the end of her life, also felt a wholly artificial and unjustified sense of guilt about her body and her illness.'

This is such a huge subject and one that Susan Sontag, of course, has written about, but it's one that you can find, going back to W.H. Auden's sort of scandalous poem, 'Miss Gee,' written in the 1920's in *The Book of the It*. This is the kind of thing, looking at medicine as if it were a sort of textual fabric, that I am personally interested in interpreting. I think that if doctors were to read they might as well read their own lives and works in this way, too. I mean that it's interpretive skills a critical skill, that humanists have to offer. It's not just a question of reading Shakespeare, it's a matter of knowing how and what to read.

NANCY SCHEPER-HUGHES: I guess I would agree pretty much with the suggestion that good poetry is not going to make a good doctor. I don't think good anthropology makes for a better doctor either. And maybe I could embody that in some of the conflicts represented by a well-known person like Paul Farmer: Dr. Paul, on the one hand, working with AIDS patients in Haiti; Professor Paul, when he's talking as an anthropologist; and then maybe Commandante Paul, when he's really trying to change things. And I see him now at a particular point in time, where Dr. Paul is really winning over the two. I admire and love Paul Farmer as both as anthropologist and as doctor—and I think of the piece that he wrote on structural violence that is the culmination of many years of his trying to understand what it is that people bring to him in the clinics in Haiti. It's not just AIDS, and it's not just drug-resistant tuberculosis. Instead, it's those much larger demands for a more just society, for better housing and for a fair shake in life.

And as Farmer becomes more and more aware of the limitations of what it is clinical medicine can do, he also becomes impatient with what anthropology can offer. He talks about these patients coming to him with advanced cases of AIDS, trying to explain what happened to them in terms of illnesses that were sent through magical means, or illnesses that are a sort of congealing of bad social relations—all of those metaphors that we live with day-to-day in anthropology. And he shakes his head and he says, 'All I want is to get more drugs into these people. I don't want to hear the stories. I want them to be quiet about them.' And on the other hand, he wants to treat the sick society, Haiti. And he puts a lot of energy into that battle.

Some years ago, I wrote a piece called 'Three Propositions' for *Critically Applied Medical Anthropology*, trying to figure out what in the world medical anthropology might offer to the practice of medicine. I was being provocative, and I said, 'Well, there's three options.' One is let's accept that the best of what medicine is essentially a kind of fabulous plumbing. And let's take the doctor as plumber and make him a better plumber because that's what people, in a sense, are looking for. They are looking for hands on their body as a kind of a machine. People do want that. They don't always want or expect doctors to answer their existential problems, but they want their pain to be diminished. And leave the shamanic task, leave the answering of these larger existential questions, to other groups or individuals in society, to the priests, to the shamans, whatever. Can we really form doctors to be both marvelous technicians as well as philosophers? So that was the good plumbing model.

Another model I would call the 'alcoholic anonymous' model for medicine—a certain amount of humility, where doctors realize they can't answer all the existential angst that people bring to the clinic, and know when to tell patients, 'I don't have an answer to what it is you're suffering from.' I was thinking of a Cree Indian boy, who was flown into a clinic in Montreal. He was mute, looking very psychotic. My

colleague, Margaret Locke, was brought in to help the consulting psychiatrist and the doctors figure out what to do with this boy. He wasn't eating, he was in a very regressed kind of state. The psychiatrist was wondering whether to put him in a mental hospital and treat him with antidepressant drugs. Margaret did a kind of an anthropological examination of this young man. What she learned very quickly through the use of interpreters and through sign language, because this child was really mostly mute, was that he had lost all his family. He was living in a post-genocidal situation. He was living and trained in a boarding school. He was missing his family that no longer existed back in the village. And now here he was flown in by helicopter to this hospital, Western medicine comes to the fore. Margaret advised—and the psychiatrist accepted the fact—that the only thing the boy wanted was to go home. Somehow she helped convince the psychiatrist that the answer was not anti psychotic drugs and hospitalization, but actually to return the boy to some semblance of family, and to let his problems be solved perhaps within the context of what was left of pre-society. So this example suggests that maybe medicine shouldn't be quite so aggressive in trying to treat the things that it really can't treat.

But I'm not so happy with that model anymore, not only because I see Paul Farmer himself resisting taking on the larger phenomenological existential causes of people's problems. It's what I'm seeing in actual practice in respect to the problem that I'm dealing with, a collapse of ethics in transplant internationally. It's precisely a kind of retrenchment by doctors in saying that they can't be the philosophers and the ethicists for their patients. The patients have their own demands that they bring, and the doctors are only there to satisfy those demands. Unfortunately, since patients now in many parts of the world are demanding fresh organs, and form patients' rights groups, notions of medical citizenship demand the right to plunge into another poor person's body to take those organs. What I'm amazed at is the failure of a kind of a humanism in the transplant surgeons, who then hide behind this very model that I'm talking about, the sort of plumbing model, and 'we can't really judge,' 'we can't second guess our patients,' 'our only responsibility is to follow orders given to us by our patients.'

What I'm saying is that maybe this plumbing model, after all, is not the best one. But do I think that teaching anthropology to doctors is a way to make them better healers? I'm not so sure, because they will tend to take whatever it is anthropology has to offer—I've seen it happen many times—and cut it down to little variables that can be included in medical education. So can you teach empathy? I don't know. Can you teach cultural sensitivity? Can you teach a kind of a radical existentialist position as represented by Cree Indian in five minutes to a group of doctors? I don't know. I'm afraid now to see medicine too detached from humanities. But I'm not so sure how you go about giving that to medicine, or what kinds of conversations need to happen.

So perhaps the third alternative is the idea of using the clinic and using the hospital as a space to launch a kind of a cultural revolution of sorts. And that's the third part of Paul Farmer, when Paul becomes both very politically engaged, as well as engaged in responding directly to human suffering; seeing medicine as a very potent site of launching a critique of who we are, and the kinds of suffering that perhaps are socially, politically, economically induced, and could somehow be responded to.

Those are just some of the thoughts that I have about this. I'm a bit of a disbeliever in the possibility of bringing together the humanities and medicine, and yet I feel that if it doesn't happen in some way, the result is really horrible.

CHRISTINA GILLIS: I am interested, as I have said, in a kind of institutional question, and I went through all those pages of the online issue of *Academic Medicine* where people had described their programs in humanities and medicine. I went through all of that in order to look at the language in which the writers described their own programs, and the sorts of examples that came up there. And these are some of the key words coming through, the terms used in describing the humanities and medicine courses. The Body in Medicine and arts is one. Communications, Relationships, and Cultural Sensitivity—these, I assume, are different courses—Ethics and Medical Humanities, Experiential Learning—that from a college, so I assume that that's a premed. These are the topics that the writers were interested in. Others: Clinical Ethics, Palliative Care and Human Values—but it didn't really say what human values were, so I'm not quite sure of that. Another one claimed to contextualize medicine by highlighting the societal context of the doctor-patient relationship. I don't know whether that's a little bit of what you were questioning there.

But the one I liked, particularly, was from the Royal Free University College Medical School in London, which started out saying, 'It is worth explicitly stating that there is to-date no agreed definition of what medical humanities is, nor, for that matter, what constitutes the humanities and the arts.' And they did say, 'We must distinguish between medical humanities and the therapeutic use of the arts with patients, caregivers, and professionals.' This is still from the London University College Med School: 'Medical humanities is an interdisciplinary and increasingly international endeavor that draws on the creative and intellectual strengths of diverse disciplines, including literature, art, drama, films, anthropology, history, and so on.'

And there's another one, too, that I particularly liked from the... is it the Kalalinska Institute in Stockholm? And it was interesting to me that these programs were in Europe, as well as in the United States. I didn't know—but, Bert, I think you said that that is the case—that this terminology of humanities in medicine is certainly outside North America as well. Here, the people in Stockholm, they explained that there's been a shift from an almost exclusive focus on medical ethics as the humanistic discipline of relevance to medical practice, a shift to history, art, anthropology, literature. And I realize what we're talking about here is disciplined knowledge. 'The shift in emphasis has set the focus on concepts like meaning, understanding, and interpretation.' That's the Swedes again. That reminded me of Sandra's comment, and I think that also comes very close to my own interest, to shift to how do we understand and how do we interpret. And that seems to me more fruitful than talking about courses that utilize humanities' disciplines in conducting a systematic inquiry into problems faced by health professionals, utilizing fiction, patients and physicians memoirs, poetry, to rethink a doctor-patient relationship. I think the utilizing, and maybe I'm coming down too hard on that, but I think that is somewhat limiting.

So when I look at—and there really were, there's a lot I read; you haven't seen that issue of *Academic Medicine*—they seem to fall into categories. One, I would call the instrumental, the utilizing people,

using arts-based materials and so on. In other places, the courses, for example, *A History of the Body*, that seems to me a course that could be taught in an English department or in cultural studies, or whatnot. It wouldn't necessarily belong to a medical student at all. I mean, that's kind of out there in the curriculum. And then the third, which is I find for myself the most fruitful, is the emphasis upon the interpretive. And I was particularly interested in that when I planned the 'Seeing the Difference' project, because I was very interested there in how poets, critics, oncologists, psychiatrists, art historians would look at, literally, look at death, look at dying. The idea of envisioning, seeing, was so important there.

So I was interested in seeing and making meaning. And I took the title of that from the critic, Regina Baroca, who wrote 'Just in case you thought there was no distinction between representation and reality, there is death. Just in case you thought experience and the representation of experience melted into one another, death provides a structural principal separating the two, see the difference.' And I think that Baroca's emphasis on difference really resonates there. So there's difference between being alive and being dead, but also difference in how we look at all of that.

And so that raises, then, the question for us in the academy—and here I'm really speaking of people who are in my kind of position—again, I'm not in the medical school, I'm in a humanities center—and I see our role as developing and facilitating new institutionalized ways of seeing. That is, we're producing knowledge, but we have to ask ourselves, particularly when we enter a subject matter like death and dying what kind of knowledge we can produce, and how shall we do that. I'm really speaking about modes of cognition, how people are trained; if people come together in a group and you're a doctor and I'm a poet, we may see the world somewhat differently. So how do we negotiate that? And, ultimately, I think it becomes very much a question of language again. How do we open up words? And there are big words. These are some of the ones that came out in the 'Seeing the Difference' conference: Absence, ambiguity, uncertainty, acknowledgement—which was Jodi's word, a wonderful one—plausibility was a word that Sandra gave us on that occasion—when death becomes plausible, when you look at the body, and something, an awareness, a certain sense of plausibility and vision.

So I could go on with that. And I'm not going to give examples from the text; I think it would take too long. I feel very strongly that when we're talking about something like death and dying, we're operating in a space that's somehow between subjective experience and disciplined knowledge, and it's pulling on both. And I think we get extremely fruitful discussion when we're in that space, but it's a space that's a little hard to define. One of [our fellows, Robin Marasco] alluded to this when she said, 'I feel we're in an in-between kind of place here.' But it was very fruitful, because I think we need something of the subjective in all of that as well, as we're negotiating this territory of language and what it means to us.

ELIZABETH DUNGAN: Webster's gives us this definition of interdisciplinary as something that both brings together, quote, 'two or more academic disciplines that are usually considered distinct.' Or as an adjective, 'Drawing from or characterized by participation in two or more fields of study, with the etymology coming from discipline or knowledge.'

I think that's interesting, because what kind of knowledge do two or more distinct disciplines give us, and how does one reference the other, or how does one impact the other? I'm interested in thinking about what is the knowledge that is conveyed by taking on more than one discipline? I think teaching in interdisciplinary settings helps us to ask that question: What is the relationship between disparate disciplines? And I think rather than just suggesting that reading literature or poetry makes us a better doctor, I think we might also ask some of the questions about what is knowledge, how do we change our way of knowing? This might be a kind of instrumental set of comments. What sorts of skills might we learn from looking at other disciplines? But I am a little bit less interested in content and more interested in skills, and specifically coming from art history, I have a naïve and deep belief that we can actually develop a sense of skills through looking. I think that there is a way of looking that might activate a sense of history so that if we look at something we might also acknowledge the way that it's embedded in prior case studies or prior examples, something that informs or shapes the very way that we look at something. And I'm looking at Tom here, because I think that the historical work around this helps us to really become self-conscious of how we see things as physicians, caregivers, or also as someone who is responding to the case studies.

But I also think that close looking is just a skill that is somewhat instrumental that we might take into the lab, might take into the hospital, or hospice, as Sandra was saying. And, of course, looking is not only a visual activity, but something that applies to text. So close looking might require, as Sandra was saying, a sense of pronoun, the tense of verb, which is actually looking back to some of the things that you've written prior to your comments today. But thinking about close looking requires a sense of where we are in relationship to what we're looking at. And that's the open door, the threshold where we are positioned.

But I also think, again, instrumentally, what are we doing, how might art history or other disciplines help us to look carefully? I think to look carefully also means to develop a sense of self-consciousness. So when we do look, what are our behaviors of looking? Where do our eyes go, and how does that actually activate a sense of empathy or compassion? How are those visual protocols scanning, diagnosing? How is that a sense of recognition, as opposed to a sense of identifying? These are all different visual behaviors, and we might not be self-conscious about how we activate each of those kinds of visual behaviors. But I think they are very different, and they have different implications for the subject that we're looking at, let alone the knowledge that we develop.

Many of the comments here have been about narrative—Guy started out invoking narrative; and Sandra helped us to see the role of narrative; Jodi in her introduction also described narration in terms of case study. I think part of narration is also the imaginative, and the route of that is image. I think key to that is a sense of the visual, which I know that both of you account for in your narrative work. But I think when we are developing a sense of case study, let alone when we are in an actual care-giving context, there is a sense of looking that is activating imagination, let alone, a sense of relation, which, again, goes back to Jodi's sense of empathy and compassion as activated through looking.

So what I am hoping to bring to the table is a set of skills about what does it mean to look, and how might that influence our role as care-givers, or our role in medicine? I came to art history very late, after working at the CDC, working in medicine, teaching at Stanford in medicine, and thinking about interdisciplinarity only within medicine. It incorporated anthropology, sociology, and obviously the biological sciences. So coming late to this, 10 years later, thinking about what does art history or narrative studies bring to this, I do have an instrumental sense of hoping that art history might offer us a self-consciousness or an awareness around what it means to look, and an awareness of what the codes are, what is embedded in what we look at.

And, then, lastly, I had prepared some comments around ambiguity, but Tina already talked about this. I think that some of the work that art historians or many of the other disciplines can bring to the work in medicine is a sense of comfort or motivation towards a sense of ambiguity. What does ambiguity actually deliver as, going back to etymology, knowledge? That it isn't secure, or concise, or a sense of clarity, but actually a comfort level with ambiguity and the facets that are activated in that.

DR. KEIZER: Beth, can you please give an example of what I should look at to develop what skill, however tiny? I was thinking of Rembrandt's '100 Guilder' print. And I would say... what would you think? What would you tell me to look at, and what skill would you hope I would develop out of looking at it?

ELIZABETH DUNGAN: The skill is around self-consciousness. So I would actually lessen the emphasis on art as a capital A, and more focus on visual culture. So what is the difference, for example, in focusing on an MRI or a CT scan versus something that is an 18th century wax model, and—again, looking at interdisciplinary, which was one of our charges for today, kind of thinking about interdisciplinary studies—what are the different ways of knowing that are activated by those two different encounters? So I would say, for example, an MRI, if we can be self-conscious around what an MRI allows us to know about a pathology, about a subject that we're studying. I think it's a very different set of knowledge than the wax model. And, again, you know, just historically bound. But when I say developing a sense of skills, I'm thinking about a self-consciousness around those different relationships. So for example an MRI, there's a gray scale, the data is digital, you have something that is not colorized, it's not three-dimensional. It might be translated that way. But it is something that is delivered in a coded way, it's mathematical, and it's delivered from a very different place from the body. In fact, to get an MRI you have to be isolated, obviously. So that doesn't activate a sense of full body knowledge, it doesn't use a sense of touch or scent, you know, all of these things, and it is also decontextualized. You might work with a lab technician, who interprets some of the data, and you might look at it on your [own].

So just becoming self-conscious around what are the modes of looking, and how that changes our relationship to our subject or patient, as opposed to some of those different models of looking.

DR. KEIZER: And what skill would I derive from your analysis or from my self-consciousness?

ELIZABETH DUNGAN: The skill is self-consciousness.

DR. KEIZER: Oh, I see.

THOMAS LAQUEUR: Guy and I have this argument all the time about whether reading or doing anything is going to make you a better person. I always tell Guy there are two words for anybody who believes that art is going to make you a better person: Richard Wagner.

And in general, if we knew how to make people good, we would have done it several thousand years ago, when we first started thinking about this subject. So I think that's really rather hopeless.

I think that if the idea is to make people more humane and to prevent abuses of human rights of the sort that Nancy was talking about, the answer isn't empathy, although empathy, historically, has been relevant in getting certain human rights campaigns going. In the medicine situation there is something that as a humanist I'm very unsympathetic to, which is this translation of issues of death and of pain into scales and models. In other words, we now have pain as a vital sign.

The thing that drives me crazy as a humanist, and Guy and I have argued about this, is this: Steve McFee was a humane Catholic doctor, who wrote a big, important medical textbook, which has this account of how doctors should deal with death. It starts at the top with signs and symptoms, and then it says management, and it goes down the page. So medical students are taught to think about death as if they were thinking literally about anything... exactly the same format. Multi-authored internal medicine textbooks, which have 64 chapters, go from infectious diseases to death, a little section on death. I suspect that medical students that do this will probably be more reasonable treating the death if they follow this protocol than if they followed no protocol. So in that sense, it seems to me it has nothing to do with humanity, it probably actually makes for more human treatment.

I believe if we're going to treat humanely, which is not causing pain, and not doing horrible things to them, some set of the medical context protocols, and in the world context laws that are enforceable is the answer, and not trying to make people better.

So that's the general view on medicine in the humanities, and making it better. Particularly, I felt that what is interesting about Guy and about Bert as doctors, and looking at it sort of from the specific? Bert said yesterday in talking to the fellows that philosophy has no place in the sick room, by which he meant is if you go into the sick room and the patient has a certain set of views about the soul going off into the next world, it wasn't your job to then give them a little discussion about whether the soul actually maintains its memories. You were not there to give the patient an account of the incoherence of their views of the soul. You were there to sort of say, 'That's fine, and I agree.' And you may well do... you know, go into the after-life in a certain way.

So I thought about what makes Guy and Bert the sort of doctors that I would want to deal with, specifically? And it has something to do with the ability to move from the auto mechanic mode, in which I trust both of them... I mean, you don't want a lot of philosophy or talk when you're having an endoscopy,

right? You just want them to look, and tell them what's there, you know, and be done with.

GUY MICCO: Do you want me to do your endoscopy?

THOMAS LAQUEUR: I don't want you to touch me.

So I think that when you have a bad back and you hate your orthopedic surgeon, it's not that he hunts ducks and it would be better if he was reading Shakespeare. It's that the hunting ducks is a total move away from language, the guy can't talk, isn't interested in talking. Well, you guys are both interested in talking in very different ways. It's a sort of disruptive talking. And it's sort of funny. Bert talked about a case of euthanasia, when he was about to hand the woman the barbiturates and his cell phone went off in the middle of the process. And he writes about this, and obviously just talked to this woman about this.

Dealing with Guy as a doctor can be just immensely frustrating, in the sense that you've got a lot of talk before you actually get your PSA test, if you ever get it, which you don't. But on the other hand, you're dealing with a man who has views on this.

So the medical relationship is mediated through this talk, which is more or less interesting, and then often more interesting. Both these doctors know when to stop. I mean, Bert did give this woman the barbiturate. It was the correct dosage. It was managed properly. I've seen Guy go into action when he actually needs to go into action, diagnosing someone. And it's the auto mechanic mode.

So I suspect that one can teach the auto mechanic mode, and one can teach the auto mechanic mode to keep people from being in pain, and one could teach the auto mechanic mode to sort of counteract the bureaucracy of a hospital through these protocols of death, dying, pain management. I don't know whether one can teach language and talking... if the idea is to make you more humane, the way to do it is much more structurally than through the humanities. If the idea is to make people, doctors, more the kind of people who would answer the question 'Why me?' I'm not sure we can teach them that, except by somehow teaching them about language and communication, and maybe seeing it as well. But it's not teaching them to be good, it's teaching them to...

WOMAN: My question is whoever said that teaching these humanities to doctors was going to make them good...?

THOMAS LAQUEUR: No, I mean, good in the sense of doing something medically better—better diagnostician, better therapist. People test this all the time. You can test them against some standard set of things, and you could say, 'Does this make you...' And then you can look at their backgrounds, and you can see where those guys who had degrees in literature and went to med school, equally good med schools, did better than those who had degrees in biochemistry from Harvard. And I bet you wouldn't see a difference.

JODI HALPERN: I'm actually rather dissuaded that there are ways in which someone could be a good

surgeon in terms of technically good, whatever you've read or not. Anybody who wants me to talk about my book on empathy, the first thing they say is, 'If you were dying, would you want a surgeon who was empathic or would you want a surgeon who knew how to do blah, blah, blah?' Of course, it does matter that someone takes a good history, and that they know how to deal with me in the post-op period, and not abandon me when I don't recovery correctly. So there's a lot to it.

But in psychotherapy boy, oh boy, oh boy, oh boy, do we have a more complicated situation—and, of course I also think that physicians, in general, should be psychotherapeutic in some ways too, so it broadens out. But, certainly, when the major practice is listening and recognizing and acknowledging, and either using language or silence appropriately, we really have an arena where this stuff matters.

And so what I wanted to ask you guys to think about with me is not so much what should people read. First I want to point out two things we're all guilty of, including myself, all the time, which is we think more about the empowered one, the healer, than we think about the sufferer in all these conversations. We always think more about what should the healer be or do. I can't picture myself actually dying. All my work is about how we have trouble imagining the future, and we have trouble imagining states we haven't been in. But it sure helps to put yourself at least incorrectly and roughly and grossly in the position of the person who is actually the sufferer here. So rather than thinking so much of what would make 'me' function as a physician, a therapist, whatever, I'm thinking about what is it really like to be the psychotherapy patient—some people say 'client,' but I say 'patient'—and then have your therapist write about you?

I'm skipping to this issue that interests me because I think it's relevant. There's a use of language in the therapy itself—I mean, if you're a good therapist. First of all, a lot of what you do is sort of non-verbal things, listening, and knowing when to shut up that's therapeutic. But that might take a lot of discernment. It doesn't mean you don't have to be subtle and sensitized to know when to do that. But it may not be that the quality of your own language as a therapist is as important as the real ability to track another person and be open to being wrong, being surprised... you know, ambiguity.

A lot of what makes for good therapy is not abusing someone linguistically. It's not making somebody feel ashamed or embarrassed as they reveal progressively layers and layers of experiences—which are social experiences, by the way, social traumas and other things—so that they can be progressively empowered to find their own language and their own description.

There is a psychiatrist at Harvard who was doing psychotherapy, and he was seeing this guy in therapy. And this guy, who was a middle-aged guy, who had a very successful career, but really impoverished social relations, started about two years into treatment to have real improvements in his ability to connect with people, and became involved with this woman in an intimate relationship. And she was a psychologist, and she said to him, 'You know, I think you have a mild version of Asperger's Syndrome, which is a syndrome where people sort of don't read emotions the same way, and don't sort of have the same kind of emotional perceptions, apparently, as people who don't have it. And so he asked his psychiatrist, who was doing psychotherapy with him, 'Do you think I have Asperger's?' And the psychiatrist said, 'You

know, I just don't think about you in those terms. I don't put you in that kind of category.' So he sort of blew off the question that way, and the guy was satisfied. And they went on to work well together. And [later] the psychiatrist said, 'You know, I'd really like to write about you because this has been such a transformative for me.' He said it all the right ways, you know, 'Watching you change and grow.' So he writes this article for the *Harvard Journal of Psychiatry* called 'Asperger's Syndrome.' And the first article is this wooden man, who was robotic in every way and...

And that's how we do it. We talk like that. We talk like that on rounds, we talk like that in articles, that's how we write in journals. And he gave the man the article to read too.

So my question is... there is one place we definitely need to use representation and interpretation and literature and art, and medical education has to go on and medical communication has to go on... How should we be communicating in a way... how could we talk about people in way that we would not need to do behind their backs? What language could we find? That's my first question.

And then my second one is the "Why me?" problem. One of the problems is whatever you do, no matter how much empathy there is, how much each person matters to themselves can never be captured by somebody whose job it is to care for a multitude of people. What we want is to really matter when it's *our* dying, when it's *our* suffering. It's sort of like the problem of it just matters for me when it's me, or it matters for me when it's my loved one, and it really doesn't translate into mattering quite the same way in a healer. It couldn't. And so that's like the problem of language. How does language not cover that up, but not make it worse for people? I think it relates to the first, about how you talk about a case.

WOMAN: I wanted to jump in on the Tom, Bert, and Nancy side, but in a way that follows up on what Jodi said. It seems to me just from listening, because I know nothing about training medical students, that it is much easier to teach people not to be bad doctors than to be good doctors. That some of the force of what everybody is worried about can be directed at getting them not to do the really terrible thing. There are actually no protocols for teaching to be a great auto mechanic, much less a great surgeon, a great psychotherapist, a great whatever else. It has to do with knack and intuitive ability to see and feel, and hand-eye coordination, and all sorts of other things that are there in person that get picked up by teacher and that go together. It has to do with training over time; it has to do with all sorts of things that cannot be implanted by an education. And that's just for auto mechanics. So I think that's the first thing to keep in mind in this discussion.

Another is that I know that both Tom and Bert care a lot about individual works of art in literature. I'm a refugee from the humanities, I have fled to what is normally called the arts, but even that phrase reeks too much of the grant proposal from my point of view. I care about art, individual works of fiction, non-fiction, painting, sculpture, drama, music, individual works, and those are the things that matter to me.

Now, one of the ways in which they matter to me is the way in which their practitioners have talked about them, and the practitioners say things like this, they're being taught to say: 'Poetry makes nothing

happen.’ T.S. Elliot is crazy, and Henry James, the novelist said he had ‘a mind so fine that no idea could violate it.’ Now, they weren’t saying this is across-the-board factual, undeniable, you can never tell me this isn’t true, they knew that everything they said had a grain of salt in it. But what they meant is these are not things to be used in some instrument, purely instrument fashion. These are things that the artist creates that exist in themselves, and have their own reasons for being, and have different reasons for being at different moments in history and at different moments in an individual’s life.

So that’s the way I think about individual works of art, and that is why I do not think they would be terribly useful as instructive materials for doctors to produce a certain kind of well-thinking, good-acting doctor.

The only other things I’d add in are that a section of ambiguity that I hear coming up around the table is, again, to pick up what Jodi said, very much on the side of the practitioner, very much against the interest of the sufferer. That is, the sufferer does not want to know that the practitioner is capable of perceiving ambiguity, that is not useful. There’s an old German saying that goes, ‘When you come to a fork in the road, the middle way is best...’ And to me it’s such a great notion that you must choose the one or the other. To fiddle-faddle in between or try and find another way is to destroy the whole thing.

And then the other thing I think that, and it needs to be kept in mind, is the importance of the individual, the word that ... comes next is ‘case.’ But ‘case’ is precisely the wrong way to think about it. The doctor who goes sailing may in the course of his sailing feel a life force within himself that he would not otherwise feel that enables him to then see it in the separate occasion, and respond to it in a way that a doctor who spends all his time reading, but doesn’t come to sense that life force in himself is not able to do. And it all comes down to the individual, and the individual encounter between the doctor and patient. And that can never be structured by an institution. Instructions are very bad for living things in that sense, very bad for uniqueness and specificity and things coming to life. I realize that medicine needs to be taught institutionally, but some allowance of the specificity of things and their unclassified ability needs to be there.

MAN: Let me bring it to a different place, I think, or a little different look. The training is cult-like, it’s a very cult-like training. To give you an example, when the interns first come in to the program there’s this big dinner. And they tell the story. And these are pretty amazing people. They’ve done many different things. For the most part, the people who come to this program have traveled all over the world, have worked all over different places. They tell their story. But the story doesn’t count for anything for the next three years. At the end of the three years—until recently the tradition had been to have another dinner—the residents would be roasted. So there would be an attending who would be picked to basically make light of that person in a supportive but funny way. And it was almost like the program was saying, ‘Okay, the three years have now past. Here’s your life back.’ The way I imagine it, you’ve let your story out, you let who you are out at that first meeting. The three years are then taken over, and at the end of the three years the roaster gives you your life back.

And what happens in those three years? William Carlos Williams talked about the first two years, there's room for storytelling. After the first two years, there's no storytelling. It's brutal. You basically lose whatever your own intuition is. You're put in a situation where you cause harm. Doing no harm is not part of the training; you're always doing harm. It's ridiculous for us to talk about doing no harm. And so then, being in this cult-like experience, it's your fellow people that you're going through with, plus your attending, who are your main allegiances. It's not necessarily the people you're serving.

So for me the humanities is a tool, not so much to make people better, but it's a return. The process of when you finish your residency, there is a period of time which could be your whole career when you're trying to return to who you were before this all happened. Sailing, or golf on Thursday afternoons, can certainly work that way and be a tool, and it probably works for some people. And why? There's a certain wisdom that doctors have done that for a long period of time, golf has acted as some sort of tool to turn them a little bit.

I think poetry in ICU in talking about death is another tool, and it's part of the tools. Yes, there are possibilities of seeing people different and learning how to interpret, learning how to read people, learning how to bring all that. I don't see that happening just yet. I mean, it's possible, it's just there's no time for it.

You learn a different way. But I see the humanities as a way of turning people a bit so that there's now possibility to return to who you were.

MAN: I'd like to speak to something that you brought up again that others have brought up, and that is, using the humanities [to make] humanists. I think that's what we do in medical school in what we're calling the medical humanities. I'll give you a specific example. First off, I would deny that I think that reading a poem makes for a better doctor—get that out on the table. Reading poetry, reading Shakespeare, you know, that's not the point. The point, I think, is that a thorough-going discussion, perhaps of a good poem, can lead to a more thoughtful, concerned physician-in-training or physician. I want to be the best physician I can be. I want to be a good doctor. I want my students to be good doctors, to become good doctors. How can I help them become good doctors, by which I mean both being technically good, understanding the biology and whatever else one needs to understand in that realm, and having what Rita Sharon is now popularizing as narrative knowledge, which she thinks can come from reading and writing literature, reading literature, reading poetry, and writing about one's experiences?

I'll give you a simple example, because I know Bert likes examples. A poem I read a while back by Robert Lowell has a line in it that's something like, 'The resident physician is full of enthusiasm but lacking imagination comes smiling to the bedside saying, 'What can we do for you today?'' And, of course, nothing, they can't do anything. They're hopeless. They're helpless, right? And I thought when I read this, 'I've been there; I've done that. I know exactly what that's like, going to the bedside, full of enthusiasm, you're on your rounds, going around, and you're perfunctorily, 'How can we help you?' 'What's happening today?' You don't really want to hear it. You want to look at the numbers, get all the laboratory tests taken care of, and yadda-yadda, and you write the note and get out. That's what you want. And the patient is there with this

experience, seeing this enthusiastic young face who is clueless, right? The resident physician is clueless; can't help.

Reading that poem for me was an opening and an understanding about the way I was sometimes, and the way I don't want to be. And I think I can say that it's helped me to remember that I don't want to be that way. And I think I can say that reading that with students, asking them to write about what kind of a doctor they want if they're sick, and what kind of doctor they want to be makes a difference to them later on. I can't prove that's true, but I think it's true. That's the kind of use of the humanities—to lead to a better outcome in how a doctor will act in the future.

I don't think you can teach virtue. I'm with Plato: you uncover it; or I'm with Aristotle: you help to reinforce it, such that it becomes a habit, and the more we reinforce it, the less likely the residency will beat it out of you, which it is known to do. The thing of professionalization will beat it out of you, or tamp it down into the mid-range.

MAN: Bert, would you agree on reading poems to the students?

DR. KEIZER: I'd say yes. But what gets you as a medical student is that you are so keen to join the gang that all these very tough considerations—I met so few clinicians during my training who would ever ask me, 'How are you doing today? Are you shy? Are you scared? Do you worry about what you have to say now?' Your first physical examination of the patient, your first rectal examination of the patient, these are rather gruesome procedures. I've never met an elderly clinician who helped me through that and said, 'Don't worry about it.' I mean, if you're not shy, you would be a pretty awful guy. But you were shy and were ashamed of being shy. And in my training, there was no space for this kind of awkwardness they get all filled up with, you kept a straight face during your first rectal examination or your first vaginal examination, which are... I mean, if you don't blush doing that, I don't know where you come from. But there was no space for blushing, because if you were a blusher in that kind of situation, then what are you doing in this professional anyway?

So the atmosphere in medical training is, if I put it mildly, just awful. Your fears and your anxieties, they are all sort of fanned out of the way. If you're lucky, you run into an elderly clinician, a very old one on the edge of retirement. They've got the space in themselves to admit their doubts. And what you say about language, there are two conversations—one in the restaurant and the other one in the kitchen. The kitchen conversation is always pretty harsh in medicine, and I don't think we're ever going to stop that. 'Will you look at the ... in bed six,' that kind of expression will never go out of the trade. This is awful. But you as a medical student, you would like some more heart-to-heart talk. I have never encountered it. At home, right, or with your fellow students, but never from the gang that you wanted to join. And I don't think medical school in America is much different. You were so keen to join up that to be humane, warm, doubtful, a bit tearful about certain situations, you kept that at home, right? Medical school is in that respect pretty callous and awful.

WOMAN: The very notion that Beth brought up of a kind of self-consciousness is really crucial here. I

was so impressed by what you said about medical training, which is at the heart of this. I wonder whether there is any other kind of training that anyone can go through other than military training that is so dehumanizing in certain ways; that's so radical. Graduate school is not like that. There's nothing other than going into the army and learning how to kill. To go into a situation where you begin with the analysis of the dissection of a cadaver, with the complete defamiliarization of the human body as you have been brought up to know it, and to understand it. It's what you want to do, it's the gang you want to join, but what it does to you, as almost everybody that I've read who has written about medical training acknowledges, is so radical that where are you going to get what you need? I'm not saying that you get it from reading Shakespeare, but you have to get some kind of analytic human ability, some ability to interpret the world and yourself in order to understand this extraordinary transformation that is wrought in you.

MAN: We have three medical students here. What they experience in anatomy, with a little influx of the humanities, which is far different from what Paul and I experienced, is radically different from what medical students now have when they're taking an anatomy class.

WOMAN: Don't you think that somehow fictionalizing the people that one gets to know as a patient is a way out?

JODI HALPERN: Oh, no.

WOMAN: You have the same dilemmas in anthropology where one at least acts as if one is very dear, close friends with people that you then must write about, and in the act of writing, you somehow objectify. But I think that the answer is simply to improve medical writing, just as we need to improve ethnographic writing all the time to complexify it, to allow different forms of language, different plot, to come into it, so that people can see their lives as more than simply '33-year-old Black male with' whatever.

WOMAN: I love that, but what's the problem with fiction?

WOMAN: Because it's a denial of what, in fact, you have actually learned in the experience with another person's pain and suffering in life. In a way, it's a cheap shot to say 'I'll do fiction instead.' The person should know... I'm totally interested in a form of writing the person had known about.

WOMAN: But if you're a wonderful writer, you can find ways to write about people. They'll never feel completely satisfied, but the main thing is do they feel violated? If they feel utterly violated you have failed. But the act of writing itself does do a certain violence, and you have to prepare people for it. But they will never get you... As one informant said to my students, Ron Beale, in the shantytown where I work, as we're all furiously taking field notes and writing people's stories, this illiterate guy says, 'This is a mystery. How do you capture someone's life on a piece of paper?' — You can do better. And that's why I think the craft aspect of all this needs to be distinguished from the goodness aspect. I think good doctoring is a craft, good anthropology is a craft, and how to make it good enough and how to make it better. Of course, you can't absolutely teach these things. You can help people be better.

One last thing, too, is I don't like the constant reduction of the humanities to poetry and to Shakespeare...

WOMAN: It's knowing the social context for where people come from, being sensitive to difference, and not running roughshod over it, because the tendency of medicine is always to universalize, to generalize. From history or from anthropology one would have more a local understanding of the situatedness of a particular kind of suffering, to bring in the difference that culture makes, in terms of how the body is understood, received, lived in. I would go against the complete, 'you can't instruct'. Otherwise, we would give up and say, 'Well, anthropologists are born, they're not made. We can't teach them the kinds of empathic behavior that are necessary to understanding.' I think you can... it doesn't make you a better person. I consider it 'as if-ness': you can't teach cultural relativism to someone, but you can teach people how to perform as if they didn't believe that their way of life, and knowing and understanding, where singular was total. You can at least go into a situation with a kind of epistemological openness, which I think is good for anthropology, it's good for doctors.

# About the Speakers

Bert Keizer is a Dutch writer and physician. As a physician in a nursing home he has written extensively about physician assisted suicide (which has been legal in the Netherlands for some years), most notably in his book *Dancing with Mr D*. He studied philosophy at the University of Nottingham in England before training as a doctor in Amsterdam.

Michael Rabow is a physician in the Department of Medicine at UC San Francisco.

Patricia Benner, RN, PhD, FAAN, is Chairperson and Professor of the Department of Social and Behavioral Sciences and the Thelma Cook Endowed Chair in Ethics and Spirituality at UC San Francisco.

## Roundtable Discussion

Elizabeth Dungan, Ph.D., is a Postdoctoral Fellow at UC Berkeley.

Oran Franco is a first-year medical student in the Joint Medical Program, UC San Francisco.

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