

**Seeing the Difference:  
Conversations on Death and Dying**

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

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SEEING THE DIFFERENCE brings together the texts of a two-day institute on Death and Dying, aimed at facilitating active involvement on the part of diverse attendees from the Arts, Humanities and Medical Practice. Differing conceptual frameworks offer different ways of understanding the dying body: the medical view of the body as a literal text for physical change, the humanist's view of the body as the site of complex layers of meaning, and the artist's creation of the body in terms of alternative explanatory systems. A video of highlights from the *Seeing the Difference* institute (*Seeing the Difference: Conversations on Death and Dying*) is also available through the Townsend Center.

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## **Preface:**

### **“Seeing the Difference/Seeing Differently”**

*Just in case you thought experience and the representation of experience melted into one another, death provides a structural principle separating the two.... See the difference.*

—Regina Barreca, “Writing as Voodoo: Sorcery, Hysteria, and Art”<sup>1</sup>

*Seeing the Difference*, the two-day institute whose proceedings are included here, took its title from Regina Barreca’s notion of “difference” but evolved from the Center’s long-term concerns with aging, social suffering, death and dying. Both on our own, and in collaboration with other units such as the Human Rights Center and the Institute for International Studies, the Townsend Center has continued to be expressly concerned with the tensions between the moral orientation that these topics demand of the humanities and the pragmatic orientation so often applied to them. Our object is to seek grounded responses and humanely valid ways of refiguring the predicaments of our time.

We were well aware of the problems that plague inquiry related to severe illness and death. One thinks of Walter Benjamin's addressing the incongruence between the concept and event of death and the multiplicity of approaches—avoidance, repetition, metonymy, particularized description of historical moments

and events—we bring to it<sup>2</sup>; as well as of Zygmunt Bauman's observation that modernity did not conquer mortality, it “categorized the knowable techniques and practices of measurable efficacy and effectiveness.”<sup>3</sup> In Bauman’s terms, we humanize mortality by viewing it as a set of problems. We seek an “enemy” and kill it. We turn to “projects” that we can handle and thereby attempt to give ourselves a sense of mastery over reality.

The aim of *Seeing the Difference* was to explore the *techné* of dying, representations of death, and what one might call an ethics of dying; but it accepted at the start a double sense of “difference”: Barreca’s view of death as separation or “difference” (a “structural principle”), and our own acknowledgement that we, in our various disciplines, also view death “differently” and develop languages that are too often particular to our own fields.

Dying bridges a no man’s land where the unfathomed and the unknowable confront the scientific and the humanistic imaginations. While death may be the vanishing point of medical knowledge and representation, it is also a point of mediation. Neither doctors nor humanists, nor artists nor policy makers, can provide answers where death is concerned; any inquiry into its cultural, scientific, and perhaps even spiritual contours must be a plural one. My aim in planning *Seeing the Difference* was to bring together three angles of perception: those of clinicians, humanists and artists. These conceptual frameworks offered in turn different ways of understanding the dying body: the medical view of the body as literal text for implementing physical and psychological change; the humanist’s view of the body as the site of complex layers of meaning to be explored through a range of interpretive strategies; and the artist’s creation of the body in terms of alternative explanatory systems that may mediate between the physical and the metaphysical, that may confront an “unknowable” or “inexplicable” and give it form.

*Seeing the Difference* explored the boundaries and the connections that pertain among these three different sites of knowledge and interpretation. Through the two days of discussion, participants joined in an effort to clarify their own understandings and to work toward the conceptualization of new forms of empathy towards those who face imminent death. It is not at all incidental that this was an extraordinary group of people. I knew many of the resource speakers from earlier

occasions at the Townsend Center, and there was no doubt that these people would bring the best of their professional experience and understanding to our discussions. But the participants were also extraordinary. Exploring the net and using electronic lists, the Townsend Center staff was able to attract participation from people who were not part of our regular constituency, individuals in a range of professional locations—including social services and health-related professions—who could bring to the institute experience and points of view that might be different from our own.

The ultimate purpose of *Seeing the Difference* was to produce, in video, print, and on-line formats, a record that could be used in other settings where practitioners are trained to work with the dying. Our project was in one sense about what cannot be figured: in the words of Dr. Frank Gonzalez-Crussi, one of our speakers, it was about absence or “negative space”; and it was about silence and the liminal. As the participants learned too, however, the institute was really about “making meaning” of what all too often appears to be meaningless. *Seeing the Difference* preceded by over a year the events of September 11, 2001. But now, with those events inscribed in our minds, imaginations, and even our history, and with the necessity of dealing with loss and emptiness on an enormous scale, our project's goal of finding meaning, of using multiple lenses to “see,” seems all the more crucial.

—Christina M. Gillis  
Associate Director, Townsend Center for the Humanities

## Notes

<sup>1</sup> Quoted in *Death and Representation*, edited by Elisabeth Bronfen and Sarah Webster Goodwin (Baltimore: Johns Hopkins University Press, 1993), p. 174.

<sup>2</sup> Ronald Schleifer, “Walter Benjamin and the Crisis of Representation: Multiplicity, Meaning, and Aesthetic Death,” in *ibid.*, p. 313.

<sup>3</sup> Zygmunt Bauman, *Mortality, Immortality, and Other Life Strategies* (Stanford: Stanford University Press, 1992), pp. 152, 163.



Session One  
**Silence, Art and Ritual**





# Editor's Note

## Session One

We begin our exploration of “seeing the difference” in a session entitled “Silence, Art and Ritual.” Launching the institute with a specifically visual example, photographer Jim Goldberg prefaces his presentation with a moving series of images of individuals he had photographed some years earlier in a Boston nursing home. Goldberg then moves on to show and discuss his work on the death of his father, an amazing series which had been commissioned for an exhibit organized by the National Hospice Organization (Hospice) for the Corcoran Gallery of Art in Washington, D.C. (later published in the catalogue entitled *Hospice: A Photographic Inquiry*). His parents had agreed to the Hospice photographs, Jim explains, because they “wanted to help people.” As both son and photographer Jim “saw” his father’s death. In readings from diary entries he made in those final days of his father’s life, as well as the images he shot, Jim explores the difficulties inherent in those dual roles. Jim Goldberg’s presentation probed the kinds of knowledge that art and ritual can provide in the realm of loss and suffering. Of the moments captured in his photographs of his father, he later wrote, “I could feel something when my father died, but I couldn’t see it.” That dichotomy Jim identifies between feeling and seeing will be seen to come up again in subsequent discussions of the institute.

Jim’s account of being there, of witnessing the death of his father as both son and artist, is followed by “Death Opens,” Sandra Gilbert’s exploration of the

ways in which the death of her husband “opened” into something “plausible,” “urgently close” for herself and her daughters, seemingly collapsing the boundaries between the living and the dead. A literary critic and a poet, Sandra Gilbert speaks in spatial terms to the notion of boundary or border that Jim Goldberg’s photograph of the watch marking the moment of his father’s death (“7:41”) suggests in a temporal sense. The ways in which funerary practices either do or do not take such borders into account are explored in Gary Laderman’s presentation, “The Embalming Century.” A scholar of religion with a focus on American rituals around death and funerary practice, Laderman gives us an account of the pivotal role of embalming in the growth of the funeral industry; embalming, he explains, allowed the notion of the “last (beautiful) look.” The embalmed body that ostensibly does not “look” dead is thus a powerful means of denying the boundaries between the living and the dead.

All of these presentations explore the regime of the visual in different ways. The panelists ask, what do we see when we look at the dead? What is the function of this seeing, for the dying and for those who survive? Does art facilitate or obfuscate our attempts to understand the experience of death? And finally, as eloquently posited by commentator Jodi Halpern, M.D., Ph.D. (philosophy), what is the function of acknowledgement—for the living and for the dead? What do we want from the dying? What do the dying themselves want? What is the relationship between acknowledgement and empathic connection? Speakers and participants grapple with these questions in the discussion introduced by Dr. Halpern, asking what cultural metaphors are open to us in the contemplation of death. If death is, as Sandra Gilbert has suggested, an “open door,” what is that space that we want to peer into, that place whose image we both desire and dread?  
—CMG

**Jim Goldberg**  
Photographer, San Francisco

In the 1980s I received a Public Art Commission to do work in a nursing home in Cambridge, Massachusetts—I was teaching at the University of Massachusetts, Boston, and I received this commission to do a permanent installation there. I spent about four months at the nursing home before I even photographed. My work is based in trust. And I don't work well just snapping pictures, although some people would say the opposite. I really feel like intimacy and trust are the guide to my work. So I used the methodology [I had used in an earlier book] of having people write on the photographs, and I extended it by using sound, smells, objects, etc., all different sizes of photographs. I don't know if you can read the writing, but I'll read it for you.

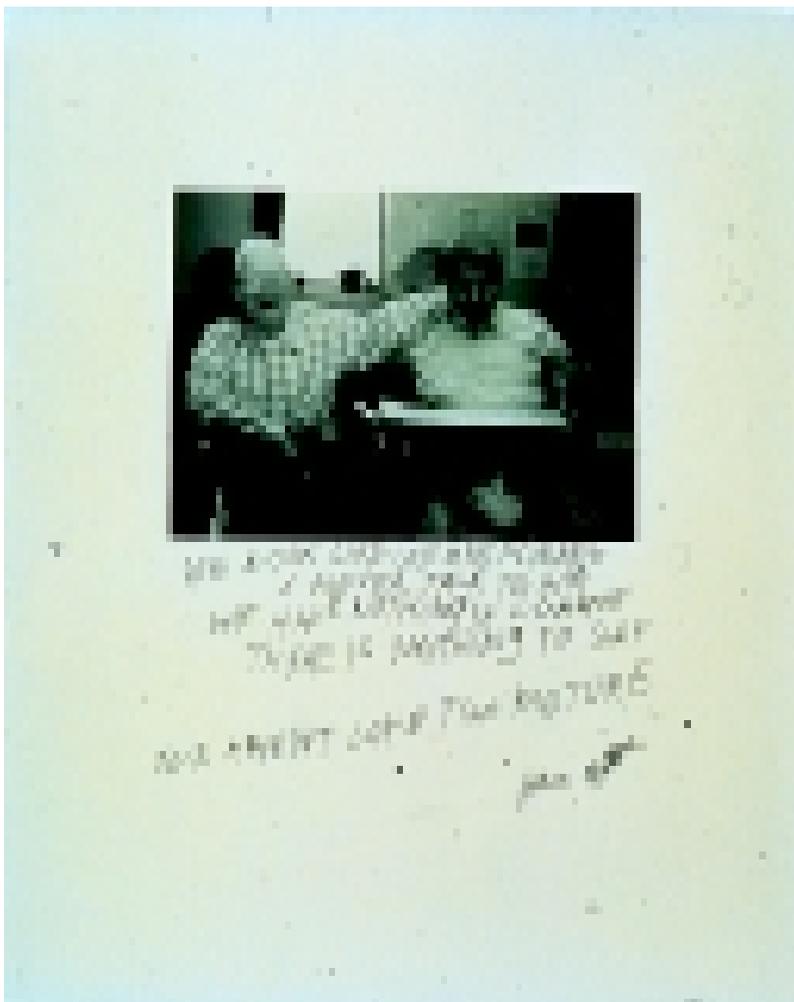
This work was not a condemnation of the nursing home industry. If anything, it was about a situation that I found myself in, photographing people who are sometimes forgotten, sometimes not, but were there for various reasons. And, really, the work is about dying, and then accepting your death.

Here, then, are some of the inscriptions written by the individuals in the photographs. A woman named Margaret writes:

*Dear Jim, I wish there was some concoction to drink so that you and I wouldn't get old. This picture is about getting old, the camera doesn't lie. This is what pain and sickness will do to you. It is a*

*disappointment. I cannot believe I look like this. I would like to see a picture of you close-up when you're 76 years old. —Margaret<sup>1</sup>*

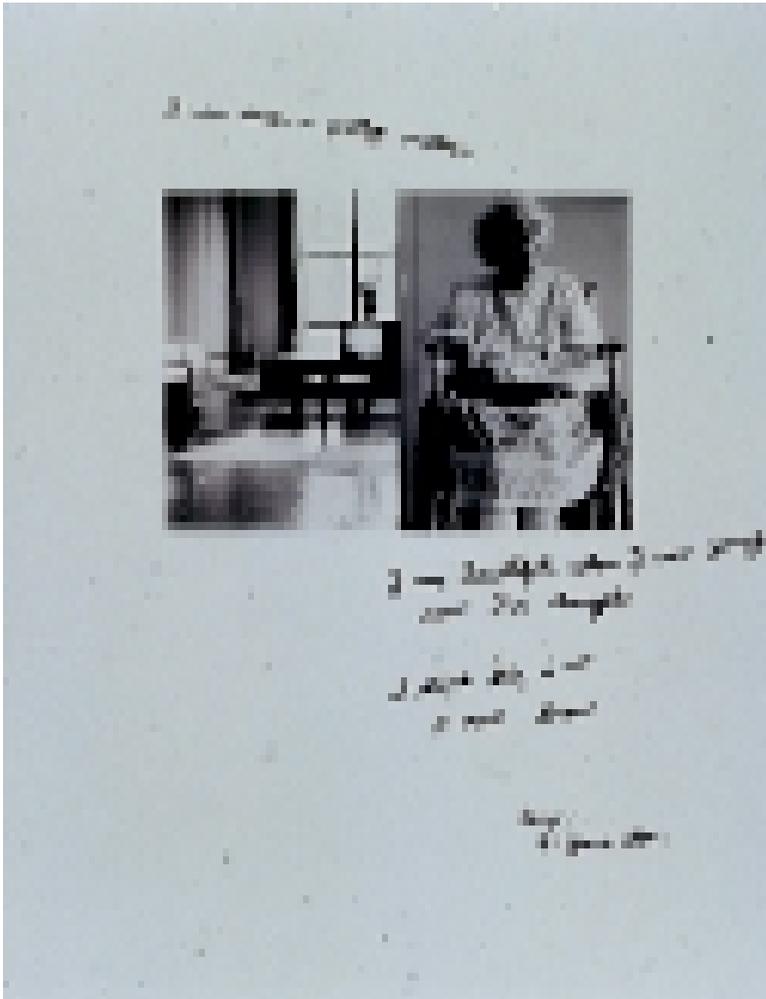
Margaret's belief that the camera does not lie is not shared by the man who writes of this photo, where he appears with another resident<sup>2</sup>:



Another man, photographed lying inert in his bed, positions himself as not really in the “world”:

*I was handsome. I had a stroke. I lie here all day long listening to voices squeaking. I'm fed up with my ailments. I'm through with this world. I want to go to a happy place.*

And Mary seems to have trouble recognizing herself<sup>3</sup>:



We can juxtapose Mary’s uncertainty in identifying herself—“I think this is me”—to another woman’s noting of her photograph, “This is a big picture, I like it. I’m hidden away. I’m all gone.” But a more optimistic note is sounded by the man of ninety-nine who wrote:

*Some old people are absolutely useless, but I’m hanging on very well. I’m going to be 99. It’s all a struggle. When I go to sleep I’m never sure if I will wake up. I’m slipping between darkness and lightness... I look pretty good, except I’m bald-headed.*

But I want to turn now to my father. In 1992, at my father’s seventy-fifth birthday party, which was basically a family reunion, we got together in Florida where my parents lived, and had a little celebration. But we also had a family discussion. My father, before I was born, was diagnosed with a disease that is very rare but is like MS. And the story goes that when my mother was pregnant with my sister—I have two other siblings, I’m the youngest—and my father was drafted for World War II and took his physical, they found out that he had this disease. He had no idea. He was having trouble walking or something like that. They gave him a 4F draft rating and told him that he had up to a year to live. This story is very important to understanding my *Hospice* photographs, because this is a man who was supposed to die and then he went out and had two other children and lived a full life, dying only at age seventy-six. But it wasn’t an easy life. He did struggle and never felt that he could reach his potential. He had that disease which continually disabled him. And then he was diagnosed—I’m not even sure when, but in the 1980s—with colon cancer. It was taken out, but within the five years, the cancer came up again, and this time in his lungs.

And so when we met as a family on that day, on his birthday, it was getting harder and harder for him to get out of the chair because of his serena myalialia, but also because of his debilitation from the the cancer. It just was getting to be too much. And we decided as a family that Hospice was the way to go. And at the same time, at the exact same time—this is a long story, I’m sorry—I got a call from the National Hospice Association, to see if I would be interested in a commission to photograph the hospice experience. Well, I had just done *Raised by Wolves*, a book on street kids. I had had enough of this negative stuff, and wanted

to do something happier. But I had to admit that at least what they offered me at the time was pretty good money, and it seemed that I had no choice. I was broke from *Raised by Wolves*. But still I really didn't want to do it, and I was really debating it. But when we met as a family, it just seemed a bittersweet blessing, that I was given this opportunity to photograph. And since I lived in California, I'd be paid to travel to Florida to do the work. And my family thought it was a good idea because they felt that this project could help people, and they wanted to help people. So I spent a year photographing my father in the dying process.

Recently my mom died, very unexpectedly. It shouldn't have happened—you can understand the anger, frustration, shock, right now, that this death incurred. She also was diagnosed with colon cancer, and she was fine—they removed the cancer. But she was on chemotherapy and she got dehydrated. And she was old enough to be of the generation that didn't necessarily ask questions of the doctor. So she basically accepted it and thought that she was sick, that there's nothing you can do, and chemo does make you sick. She got dehydrated, and as she started getting better, she had a heart attack and died. Thus, my newest work, which I don't have today, will be about her death, combining it with this. What I hope to do is work on a new book that's about Hospice, my daughter growing up, my own divorce, and then my mother dying—about things falling apart and things coming together again. So that's the context of how I'm showing this work today.

This is Fran. My father's discomfort created tensions between my mom and my dad. She was care-taking; he was complaining. And I was there as a mediator. In the meantime, Fran [the Hospice caretaker] became almost a love object for my dad. I mean, at least in theory. He really loved her. She was the one from Hospice that he connected with. And part of what allowed me to do this work about Hospice was their



relationship, and the fact that she got him through every day, by the jokes, the stories, and the advice that he would give her about how to set up her VCR and stuff like that.

It would be bad politics for me to say the work is not really about Hospice. I went out of my way not to make any kind of propagandistic work about Hospice because I felt that it spoke for itself, by the fact that it allowed our family to be a family together, and allowed me to photograph. But really, this work is about birth and death, and my relationship with my dad.

I had my mother keep diaries. I kept a diary, too. A lot of my work revolves around my writing now. I'm getting to be a better writer as I get older.

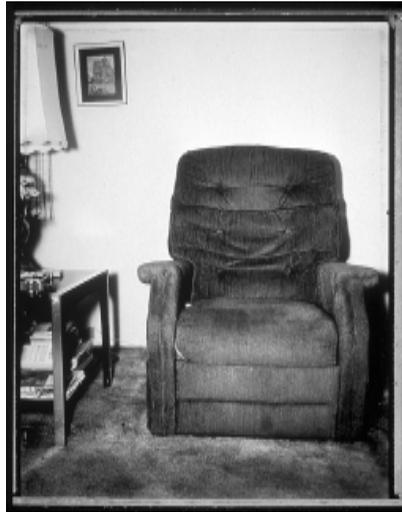
Let me read you something, if I may indulge myself. I got the call before Christmas that my father was going downhill. Hospice thought he was going to make it for a while longer. My mother said no. So I went there. And my father died on Christmas Day of 1993. Because of that, everyone from Hospice was on vacation. So we had to get outside help to come in. On December 25 at 6:30 a.m., this is what I wrote:

There is an insecure tap-tap-tap on the door. "It's me, Adam." Adam is the helper, the hired help. "Your mother wants you to come out here now." Mom is collapsed over Dad, crying and calling out, "I can't understand him. What do you want, Herb? Do you want me to raise the bed higher?" Mom implores me to do something. "He's not breathing well. Can you help him? Jim, you must help." I moved to Dad and put my ear to his lips. Faintly, he says, "I can't breathe." I ask about the oxygen, and Adam says he tested it 15 minutes ago. My father looks like a lunatic. I lean closer still, and he says, "Say thank you." "To who, Dad?" I ask, going through the list of possibilities, and, finally, arriving at Adam. Dad agrees with his eyes. Even in dying, he is graceful. All of a sudden, with as much force as he can muster, Dad yells, "Chair!"

His chair is the place from which he ran the TV and the radio, and stuff like that. And he decided that that's where he

wanted to die. And Adam was not trained like Hospice people were to move him, to transition him. So I tried to do it myself, and I was stuck. And a dying person weighs a lot, as you must know.

I'm determined to get Dad into his chair. I call Hospice and leave a message for the Green Team Nurse to call. I direct mom to comfort Dad. Mom begs me, "Help him breathe, Jim, help him breathe!" I turn up the oxygen machine. Dad's eyes are glazed



over. I tell him, "I'm right here, Dad." "Chair," he whispers, the words not quite discernible. "I'm trying, Dad, I want to call Fran." "No, it's Christmas and I don't want you to disturb anybody," Mom says, "It's not right." "Mom, I don't know what's right now, I just know that he's dying and I've got to get him to his chair." "Don't be so negative, Jim," she says. "Your father will make it; he always has." Mom kisses Dad, while I photograph their last time together. It's an incredible star shining in your eyes as tears fall down on this moment. I see that Mom is about to offer coffee and cookies to Adam. He is nice, but I don't want him here now. "Not now Mom," I declare, "we need to be alone with Dad." Adam leaves. I realize that all the things that my father couldn't be in his life don't matter now. I think that he is a strong, focused, great man. I must get him to his chair. Time speeds up. Dad is losing consciousness, mumbling coma words. "What's he saying, Jim?" Mom asks. "I don't know, Mom. 'Chair,' I assume." Hospice calls back. I describe how he can't breathe, and Rena the nurse says, "It sounds like the death's rattle." She tells me to rub Dad's hand and help him push

forward, and that she'll check back in an hour. I'm pleading to Dad, "Hold on until Fran gets here. Can you hear me? Can you hear me?" No more whispers, no more breathing, no more nothing.



7:41 a.m. He is dead. My mom is begging me to give him more oxygen. I explain that it won't help. Hospice calls. Someone will be over in thirty minutes. Mom is crying, and goes out to get the paper. She comes back. It's a beautiful clear cold morning. The headlines read: "Florida Gets a Wintry Slap for the Holiday, and Bethlehem Christmas is Joyous and Political." The house is still warm from the oxygen. Dad is now cold.

### Notes

<sup>1</sup> The italicized quotes are from inscriptions written on the photographs by the photographic subjects. Other quotes are from Jim Goldberg directly.

<sup>2</sup> John inscribes his photograph with these comments: *We look like we are friends. I never talk to him. We have nothing in common. There is nothing to say. We aren't like the picture.* —John Mason

<sup>3</sup> Mary writes on her photo: *I was such a pretty mother. I was beautiful when I was young. Now I've changed. I think this is me. I don't know.* —Mary, 81 years old.

Images from:

Goldberg, Jim. *Hospice: A Photographic Inquiry*. Edited by Dena Andre, Philip Brookman and Jane Livingston. Essays by Marilyn Webb and Jane Livingston. (New York and Boston: A Bulfinch Press Book, in association with the Corcoran Gallery of Art and the National Hospice Foundation), 1996.

## **Sandra Gilbert, Ph.D.**

**Department of English, University of California, Davis**

### Death's Door I: Death Opens

Paris. November 1, 1999. Today is All Saints' Day, and tomorrow will be the day of All Souls, also called the Day of the Dead. Once, before the Church embarked on a program of sanitizing and sanctifying, these days marked the Celtic *Samhain*, a holiday when, according to some, the walls between this world and the "other" are "most transparent," the souls of the dead driven toward us in multitudes, like swirling leaves. But even now Christian festivals preserve a trace of the old mysterious connections between "here" and "there," between the realm of the flesh and the realm of invisible spirits, that shaped this time for centuries. All Saints' Day, writes one cleric, "commemorates the holy ones of all ages and stations whose names are known only to God," while All Souls' Day celebrates "those who have died but not yet attained the presence of God." And there is "an old Scottish belief that anyone born on All Souls' Day will have 'double sight': he will be able to see the spirit world about him and have command over the spirits he sees."

On this feast of All Saints it's exactly eight years, eight months, and twenty-one days since the sunny February morning when two orderlies arrived to wheel my husband of thirty-three years into the northern California operating theater where he had a routine prostatectomy from which he never recovered. Though he was in robust health apart from the tumor for which he was being treated, Elliot died some six hours after my children and I were told that his surgeon had successfully removed the malignancy. And for the first six months after he died, death suddenly seemed plausible—not a far-off threat but urgently close—as if the walls between this world and the "other" had indeed become transparent, or as if

a door between the two realms had swung open. For the first six weeks after he died, death even seemed not only rational but right, or at least appropriate, as if I were already standing in its doorway and needed merely to keep walking toward where my husband now was.

If he who had been bone of my bone, sinew of my sinew, could do this mysterious thing called “dying,” then so could (and clearly *should*) I. Not, I have to add, as a ceremonial acknowledgment of widowhood, a form of *sati*—or a heroic gesture like the act said sometimes to have been chosen by a bereaved wife in imperial China, “who arranged to hang herself publicly on the death of her spouse”—a self-immolation “not regarded as suicide but as a heroic victory over death.”<sup>1</sup> No, my surprising sense of the plausibility of death had little in common with a “heroic” leap toward oblivion or even, indeed, with any fantasy of suicide, as I understand the term. It was more, I think, like a move in a board game, an eerily competitive mirroring of another player’s strategy: “If *you* can do that, so can I.” But without the hostility implied by the word “competitive”; with, instead, a kind of eager, helpless mimicry. As in, “Oh I see, so *that’s* what’s next!”

Or perhaps, to offer an alternative explanation, my necessitous sense of the nearness of death was akin to the protective feeling reported by the journalist Lisa Schnell, a grieving mother who notes that just after the death of her eighteen-month-old daughter she and her husband “wanted to be with Claire right then, cradling her perfect soul as we had cradled her imperfect little body all her brief life. We wanted to be dead with her.” Adds Schnell, “I wasn’t suicidal—I didn’t want to *make* myself dead—I just wanted to be dead with Claire. I raged at the injustice of the fact that though she had needed me to give birth to her, she didn’t need me to die with her.”

As soon as I read Schnell’s words, I recognized their uncanny logic. Of course! Elliot and I traveled, shopped, ate, slept, dreamt together. Wasn’t it perfectly rational to suppose, just after he died, that we should be dead together?

And now, as All Saints’ Day draws to a close here in Paris, soon to blend into its close cousin, All Souls’ Day, I’m reminded again of the close, invisible threshold toward which so many mourners are drawn. The streets are almost sepulchrally still this afternoon. “*Toussaint*” is a *jour de fête* throughout most of Europe. Almost everything’s shut today, with no bread to be had in the usually

baguette-laden *quartier* where I live.

According to a Web site I just found, medieval priests instituted the feasts of All Saints and All Souls because they feared the charisma of *Samhain*, a harvest festival whose acolytes celebrated this primordial Hallowe'en and the next day, "All Hallows Day," as the doorway into "the season of death revels, the period of misrule from dusk on October 31 to the Winter Solstice." Celebrants of such morbid revels hung lanterns, perhaps the ancestors of our jack o' lanterns, to guide wandering spirits. To nourish the ghosts there were "soul cakes," maybe the forerunners of the "treats" we give today to would-be tricksters. Since an event so resonant couldn't be entirely repressed, the Catholic clergy had to transform it into something less threatening. *Samhain* acknowledges the power of death and the dead over us. The Church had to convert this holiday into its opposite, a day when we have power over the dead, for, as always, the Christian mission is to conquer death.

Where the ancient Celts are said to have sought to honor (and perhaps appease) the dead with offerings of "soul cakes," the Church's attitude toward those on the "other" side is both more austere and more ambitious. Declares the *Catholic Encyclopedia*, the "theological basis for the feast [of All Souls] is the doctrine that... souls which are not perfectly cleansed from venial sins... are debarred from the Beatific Vision, and that the faithful on earth can help them by prayers, alms, deeds and especially by the sacrifice of the Mass." Perhaps in keeping with this injunction some of my neighbors are going now among the tombs of Père Lachaise with flowers and prayers. A misty *grisaille*—damp gray—with a hint of winter in its breath unfolds a chill in the little court I'm looking out on, though there are still impatiens cascading out of the tubs flanking the doorways. And with its belated blooms, its wintry mist, the court itself seems an emblem of the "transparence" between the worlds of the living and the dead that supposedly defines these days, whether they're Christian or pagan feasts. At such a time, in such a place, it seems right to try to understand what it meant for death, suddenly, to seem "plausible," as if it had out of nowhere, unnervingly, opened itself to me.

"Death opened, like a black tree, blackly," Sylvia Plath wrote, brooding on the shock of her father's death when she was seven. A bereaved adult, I too was shocked and astonished when my husband's death opened and unfolded itself

like the chill in the court, as if it must now be part of a quotidian “season of death revels” leading to the winter solstice.

Well, not exactly *revels!* When my daughters and I were led into the small, pale, shiny hospital cubicle where Elliot lay after what must have been a terrible six-hour battle to survive the surgery that killed him, we found ourselves at first, as we stared at the silent stone version of himself that he had become, in a space that was bleakly filled by corporeal substance. This death that had suddenly, gigantically, opened around us—opened perhaps rather more like a huge black umbrella rapidly unfurling than like a stately black tree unscrolling its branches—*this* death was hardly the soothing presence that Walt Whitman describes in “When Lilacs Last in the Dooryard Bloom’d,” his great elegy for Abraham Lincoln, as a “dark mother always gliding near with soft feet,” a “strong deliveress.” Serious and *material* rather than maternal, this death forced me, horrifyingly, to confront the metamorphosis of a body I had loved into a dead thing that now appeared to be the material of fate itself.

Yet at that first shocking moment in the shiny cubicle, gazing at the uncannily familiar image of *Elliot*—not at *what had been* “Elliot” but at what *still seemed to be* “Elliot”—death itself was made eerily plausible by my husband’s lingering presence in the midst of it: by the slight rueful smile on his face (that might have been the relic of a grimace of pain or fear); by the tilt of his head that was even now (after what we later learned had been a tracheotomy performed by the “Code team”) so customary, so comfortingly *known*; by his shaggy eyebrows, as unruly as ever; by his hands (carefully folded on the white coverlet, maybe by a thoughtful nurse) that were still, though so frighteningly motionless, *his* hands.

He wasn’t there, but he was *there*. And his *thereness*, his presence at the center of massive absence, was what made death plausible, what flung it open like a door into an all-too-easily accessible space or like a black umbrella defining an indisputably real circle of shadow into which it would be astonishingly simple to step.

Meditating today on this curious sense of the plausibility of death that my husband’s utterly unexpected and therefore quite implausible death paradoxically bestowed, I realize that such a feeling must account for traditional images of dead people “living,” as it were, on “the other side” of a sometimes permeable, at least

semi-transparent barrier. So and so is “gone,” we say. But gone where? When one “goes,” one goes *somewhere*. Somewhere plausible, which is to say *feasible*, practicable, indeed (paradoxically) *livable*.

Death opens—and one goes into it, as into a place. The kingdom of the dead, the underworld, the “other side”: it doesn’t matter how one imagines the place, what’s important is that it’s a *place* and that, given the weird familiarity of the body of the dead one—its quality of both being and not being the beloved—the place where the dead one has “gone” must also be weirdly familiar.

Geographically, I now think I rather obscurely felt, at that moment of deathly nearness, that death must be as plausible as any hitherto foreign country to which one might move—not travel, but *move* with all one’s goods of memory and stores of thought and trunkloads of hope. As if, in other words, “going” into death were like uprooting oneself and resettling, say, in France—death being after all “just,” in Hamlet’s words, another “undiscovered country.”

And in that case, given the logic of the metaphor, death-as-plausible-country must also be or have a language that one might struggle to learn, the way one struggles to learn French. If (or, rather, when) you move to death, you’ll learn its language through the educational process known as “total immersion.”

Prayer, the Church would say—especially on this *jour de fête* of *Toussaint*—is the tongue in which one addresses the dead and the tongue in which one speaks of them, whereas the celebrants of *Samhain* would argue that we signal those on “the other side” of the frontier between here and there, our country and their misty place, with pumpkins and turnips carved into lanterns or with hilltop bonfires and perhaps rattling calabashes. For in many cultures, “mere noise”—“explosions, the firing of guns, the beating of gongs”—is considered the proper way to talk to the dead, either to invoke them or to still them.<sup>2</sup>

Whether one whispers prayers, shouts imprecations, tolls a solemn bell or bangs a drum loudly, though, one is seeking to speak the language of death, to address those who seem so indisputably *there* on what George Eliot, writing of the nonhuman world, called “the other side of silence.” The dead were once of the human world, yet now they too are on the other side of silence—right there, like trees, fish, flowers, butterflies—to be addressed in solemn apostrophes or to respond in what rhetoricians call “prosopopoeia,” the imagined speech of those

who may appear to be absent or unreal but are *truly* there because they are present to poets and other, perhaps more pious, interlocutors.

On the midnight richly described in “All Souls’ Night,” the verse epilogue to his mystical prose work *A Vision*, William Butler Yeats sought to invoke the dead by offering them “two long glasses brimmed with muscatel,” whose aroma a ghost might drink,

For it is a ghost’s right,  
His element is so fine  
Being sharpened by his death,  
To drink from the wine-breath  
While our gross palates drink from the whole wine....

Yeats longed for the dead to visit him at the solemn hour when he heard “the great Christ Church Bell/And many a lesser bell sound through the room,” because he was certain he had learned the secrets of the spirit world, had “mummy truths to tell/Whereat the living mock[ed].” And on that night of the old Celtic *Samhain* the Irish poet struggled like a neophyte sorcerer to summon the spirits of dead friends. Yet perhaps because death *hadn’t* plausibly opened itself to him, he seems to have been left stranded among the living, disconsolately confessing that he’d be willing to confide his “mummy truths” to any ghostly listener.

The truly bereaved are far more certain of deathly presences and hence of the plausibility of death itself. For instance, although (or perhaps precisely because) “death opened, like a black tree, blackly,” Sylvia Plath’s father was almost inescapably present to her, his voiceless voice “worming through” what she envisioned as a “black telephone” that she had to cut “off at the root” in “Daddy,” her love/hate elegy for the lost parent who had been figuratively reincarnated in her faithless husband, Ted Hughes. And more lovingly, more hopefully, Thomas Hardy believed he heard his dead wife Emma “calling” to him after her “great going” into death. “Woman much missed,” he mourns in one of his finest elegies, “how you call to me, call to me.”

Yet of course even Hardy was tormented by uncertainties. From where did Emma call, how, and in what form? “Can it be you that I hear?” he wonders, demanding “Let me view you then,” and, by implication, commanding (as Horatio

commands the ghost of Hamlet's father) "Speak, speak. I charge thee, speak."

Hardy's indecision about his wife's "prosopopoeia" dramatizes the mystery of Hamlet's "undiscovered country" even while his attention to what at least *might* be her "voice" emphasizes the plausibility of that puzzlingly unknown and familiar place. His stanza beginning "Can it be you that I hear?" is followed by utterances of skepticism and near despair:

Or is it only the breeze, in its listlessness  
Traveling across the wet mead to me here,  
You being ever dissolved to wan wistlessness,  
Heard no more again far or near?

Thus I; faltering forward,  
Leaves around me falling,  
Wind oozing thin through the thorn from norward,  
And the woman calling.

But surely such "faltering forward" across the "wet mead" into a vortex of oozing wind is dangerous! Surely, as he stumbles after the all-too-plausible "calling" of the dead woman Hardy risks staggering across the border into death itself, that all-too-near country. Marcellus and Horatio know this peril. When Hamlet, recognizing his father's ghost, declares "I'll follow it," they seek to restrain him. "What if it tempt you toward the flood, my lord," demands Horatio, "Or to the dreadful summit of the cliff...?" And Plath too encountered such a threat, famously confessing to her dead father in "Daddy" that "At twenty I tried to die,/ And get back, back, back to you."

Nor is a silent ghost less dangerously seductive. Even if the "black telephone" is off the hook, even if the "calling" seems to cease, the plausibility of the dead one draws the mourner like a magnet, as Plath imagines herself to have been urged "back, back, back" at the time of her first suicide attempt. Dead King Hamlet is speechless at first, until his distraught son cries "Whither wilt thou lead me? Speak." Haunting his lost wife's childhood home in Cornwall, Hardy echoes the Danish prince, as he falters half-blind among the misty moors and cliffs of the

past, writing in “After a Journey”:

Hereto I come to view a voiceless ghost;  
Whither, O whither will its whim now draw me.  
Up the cliff, down, till I'm lonely, lost,  
And the unseen waters' ejaculations awe me.

Was my dead husband an Orpheus leading me, his Eurydice, not out of but *into* the kingdom of death? Perhaps, through the process of unconscious revising and reversing that Freud describes in *The Interpretation of Dreams*, the old myth has the plot exactly wrong. Perhaps the story of the poet and his lost beloved isn't a tale of a failed attempt at resurrection, with Orpheus striving to lead his bride away from the lower depths of Hades into the upper air of the living, but rather a myth of immolation, in which the mourner follows the dead one down into the increasingly real, dense, and plausible shadows of the grave, unwittingly faltering across the fragile border between life and death the way, during *Samhain's* “season of death revels,” a traveler who has missed his path might be tricked into crossing the frontier between this world of the “too too solid flesh” and that “other” one that only *seems* to be insubstantial and fantastic.

When the young D. H. Lawrence was mourning the mother whom he had loved, as he once told a friend, “like a lover,” he felt the borders between life and death dissolving, as if the very categories of the living and the dead were losing their usual meanings, so that the town in which he lived began to “glimmer” with “subtle ghosts” who might be the dead walking among the living or the living appearing in the guise of the dead they must inevitably become. Addressing his lost mother in “The Inheritance,” he claims his grief as a gift of transformed and enhanced perception, almost like the privilege of “double sight” that, as traditional Scottish belief has it, belongs to anyone born on All Souls' Day. “I am dazed with the farewell,” he admits, “But I scarcely feel the loss,” for

You left me a gift  
Of tongues, so the shadows tell  
Me things, and the silences toss

Me their drift...  
So I am not lonely nor sad  
Although bereaved of you,  
My love.  
I move among a townfolk clad  
With words, but the night shows through  
Their words as they move.

And in another poem, the eerie “Troth with the Dead,” he sees a “broken ... half a moon” lying “on the low, still floor of the sky” as an emblem of his own unswerving fidelity to his dead mother, the “troth with the dead” that he is “pledged to keep.”

Yet such a troth—virtually an incestuous betrothal—to the dead is as dangerous to this poet as the half-blinded, “faltering” pursuit of Emma might have been to Hardy, or as Plath’s efforts to get “back, back, back” to her daddy surely were to her. The keeper of a “troth with the dead” knows even better than Hardy did what Horatio and Marcellus fear: the “calling” of the dead one so eloquently described by Hardy may be dangerous, may indeed be a “Call into Death,” as the title of Lawrence’s most explicit poem on this subject has it:

Since I lost you, my darling, the sky has come near,  
And I am of it. . . .

And I am willing to come to you now, my dear,  
As a pigeon lets itself off from a cathedral dome  
To be lost in the haze of the sky; I would like to come  
And be lost out of sight with you, like a melting foam.

Is it the dead one, then, who is the Orphic singer, the chanter of mysteries, inviting us through a suddenly opened doorway, uttering a strange and breathless call into what once seemed all a darkness but has now become unexpectedly luminous and at least as plausible as “the haze of the sky”? What, though, if the dead struggle to voice their urgent claims and needs but we don’t

hear them? Perhaps the mourner intuits a *nearness* from the “other side”—the estranged dimension that spirits supposedly inhabit—yet the call from the dead is inaudible. Imagine, then, the frustration of the despairing spirit, speaking without sound or substance! In “The Haunter,” one of the most poignant examples of elegiac “prosopopoeia,” Hardy evokes the pain of his ghostly wife, who cannot “let him know” how close her dead self is to his living one.

He does not think that I haunt here nightly:  
How shall I let him know  
That whither his fancy sets him wandering  
I, too, alertly go?—

And in a very different but equally bittersweet gesture of prosopopoeia, Dante Gabriel Rossetti imagines the speech of a dead woman just as her lover, left behind on earth, must himself *imagine* it. Rossetti’s “blessed damozel” presses so fervently against the golden *bar* of heaven, barrier between herself and her still-living beloved, that her bosom “warm[s]” it as if she were still alive with fleshly desire. And standing, yearning, “on the rampart of God’s house,” she longs, serenely, for her lover’s death:

“I wish that he were come to me,  
For he will come,” she said.  
“Have I not prayed in Heaven?—on earth,  
Lord, Lord, has he not pray’d?  
Are not two prayers a perfect strength?”

In “The Raven,” Rossetti once declared, “I saw that Poe had done the utmost it was possible to do with the grief of the lover on earth, and so I determined to reverse the conditions [in “The Blessed Damozel”], and give utterance to the yearning of the loved one in heaven.”

As (more obviously and famously) in “The Raven,” a perpetual chilly *Nevermore* provides a kind of ground bass to the utterances of mutual desire that cross the gulf between the lovers. Although in the gaze of heaven and in her own thoughts the damozel “scarce had been a day/One of God’s choristers,” her

survivors know she's been dead ten years, and her grieving lover, feeling her death has already lasted "ten years of years," intuitively her presence as a powerful absence:

....Yet now, and in this place,  
Surely she lean'd o'er me—her hair  
Fell all about my face....  
Nothing: the autumn fall of leaves.

Those who seem so near, whose country has become so incontrovertibly real to the mourner, are yet so far! They're inhabitants of a distant land that is nevertheless absolutely ours! And perhaps the impulse to elegy itself arises from our sense of the simultaneous nearness and farness of their place, arises because we feel the dead are so near that we must speak *to* as well as *about* or *for* them—because, that is, we wish to converse with them as if we were in their presence while lamenting what, at least intellectually, we understand to be their absence.

To readers who have never mourned, the elegist's intimacy with death must seem like ghoulishness. Such apparently unseemly intimacy may be what frightened the Church about *Samhain*, with its welcoming rituals of lanterns and soul cakes. But those who mourn, those who summon the dead while intuiting and perhaps resisting their calls *into* death, know that it is essential to speak of death and the dead because if those who have died are still part of us even while they are part of death, then death is part of us too.

I have to confess here, however, that although my husband's death made death itself so plausible, he never sang to me from beyond the grave, nor did he call me in formal verse. He simply put death *there*, in the middle of my life, because he was there himself, in the center of death. And once, yes, he did appear to me in a dream, maybe a week after he died, looking forlorn. "It's so cold here, Sem," he complained, giving me my college nickname. "So cold." He had been exiled, so it seemed, in the mysterious but suddenly plausible ring of darkness that had unexpectedly opened around us both. He was shivering and sorrowful.

In almost every culture around the world, writes the anthropologist Nigel Barley, it is "above all the dead that feel desperate grief and loneliness."<sup>3</sup>

At the end of Rossetti's poem, the not-so-blessed damozel gazes

forlornly down from the vertiginous steep of heaven, strains against “the golden barriers,” and weeps.

“I heard her tears,” confides her lover.

How could I not have wanted to follow my husband, to warm him, to comfort him, to “be dead with” him?

### Notes

<sup>1</sup> Nigel Barley, *Grave Matters: A Lively History of Death Around the World* (New York: Henry Holt, 1997), p. 87.

<sup>2</sup> Barley, p. 30.

<sup>3</sup> Barley, p. 31.

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### Why Embalm?: The Lifeblood of an Industry

From the early part of the twentieth century, funeral directors and others in the industry have offered a variety of explanations for the presence of embalming in American death rituals. While some emphasize public health and sanitation, others stress the solace the body provides to grieving survivors, and still others champion scientific advancements in the preservation of the dead, most agree on one point: embalming is the bedrock of the industry. For funeral directors to convince the public, and themselves, that they are indeed professionals who provide important services to the living—services that depend in large measure on the accessibility of pleasing, familiar-looking corpses that speak to the life lived and disguise the cause of death—embalming had to be located at the center of an elaborate regimen of technically sophisticated skills, bureaucratically informed practices, and culturally convincing symbolic actions that accompany the exit of the body from living society.

Within the first quarter of the twentieth century, embalming became the enduring signature of the nascent American funeral, the lifeblood of the quickly growing industry. Although it was in the process of becoming fully institutionalized as an American practice—through the establishment of schools, professional societies, legal regulations bearing on licensing and use of chemicals, etc.—some uncertainty about its future crept into public self-reflections of funeral men, especially the pioneers who began to see a new generation of funeral directors appear. Howard Eckels, chemical manufacturer and founder of the Eckels College of Embalming in Philadelphia, wrote in his 1921 article, “Can Embalm-

ing Be Saved?":

Those of us who have given a lifetime of study and thought to the subject know how many illusions, how many will-o'-the-wisps have flitted across our paths during the past ten or twenty years. We cannot expect, however, that those of another generation will have our viewpoint or get the entire benefit of our perspective.... Embalming is worth saving, because if it be weakened the whole structure of our professional relations with our clients falls, and we again become merely commercial men selling a commercial product, the casket, along with unprofessional and unskilled service.<sup>1</sup>

Eckels understands embalming as a practice that stands outside of the mundane, economic transactions that take place between client and funeral director, even though clients ultimately pay for it. The empirical, scientific discoveries made by American funeral men have led to tremendous progress in embalming, and the embalmed body, for Eckels and others, is the vessel which allows funeral directors to transcend their status as “commercial men selling a commercial product.”

What is it about the embalmed body that transforms the funeral into something more than a simple financial transaction of goods and services? From early in the twentieth century a series of responses to this question emerged, with most still present on the lips of contemporary funeral directors. One of the most common justifications for embalming by individuals within the industry is that it has public value: to embalm the dead is protect the living from deadly influences. The virtue of preservation is another typical reason given by funeral men and women, which is not surprising considering the keen interest in ancient Egyptian practices. Although preservation is key, the logic of embalming is also supported by critical modern arguments about human psychology, universal religious sensibilities, and the aesthetics of death.

An embalmed body is sanitary, and therefore not threatening to the living; an embalmed body can be preserved, made to fit into the hectic schedule of people traveling long distances to attend the funeral; but most significant to funeral directors, an embalmed body must be seen in order to have value as a source of familial and communal healing. Contrary to the common, familiar critiques against the industry, these ritual specialists argue that the cosmetic aspect

of what came to be known as “restorative art” does not lead to the denial of death, but rather to a safe, humane confrontation with its undeniable reality. Embalming allows survivors an opportunity to look death square in the face and in its still silence and recognize the finality without experiencing the terror and dread typically associated with corpses and the processes of dying. One writer coolly and rationally gives the following explanation for embalming: “Humanity, being socially and sentimentally minded, derives a great deal of mental satisfaction from mental images. The last view of a departed one may bring consolation if evidences of disease and suffering have been eradicated.”<sup>2</sup> For this and other reasons, embalming is often identified as a “healing art” by many within the industry.

In an article from the 1920s, C. F. Callaway, a well-known educator in the field, notes the increasing demand among funeral men, and even some women, for instruction in embalming techniques. After informing his readers that “Accidental deaths are decidedly on the increase,” he makes the argument about the artistic merits of embalming and the embalmers’ aspirations toward what many artists strive to achieve, an idealized representation of a reality no longer present—in this case, a living person: “The rebuilding of features is really a work of art. It all is the work of an artist and requires the technic [sic] of an artist to fully perform this feat.... In every human face there are certain points that are essential and that we must bring out if we would produce a face that is in any degree natural.... We must see not the face before us, but the face we would have before us.”<sup>3</sup>

The artistry involved in preparing a body for its final appearance requires many essential components, including: appropriate training and practice, if the living are truly to transcend the suffering and disorder that accompanies the death of a close relation; a desire to engage in this kind of work that few people in society possess, which contributes to a sense of election among those who make the decision to enter the guild; and a commitment to serving the public, who demand that specialists oversee the removal of their dead in an acceptable, respectful manner.

How a dead body looks to survivors is of the utmost importance to individuals within the industry. A successful funeral is one with an open casket and an embalmed body that appears familiar and nonthreatening to the visitors. Significant increases in accidental and work-related deaths, as well as the appearance of new forms of disease that ravage the body, led embalmers to experi-

ment with reconstructive surgery on the cadaver. Indeed, an entirely new form of surgery emerged in the first half of the century that relied on inventive surgical interventions and innovative artificial manipulations, including the utilization of cosmetics, to restore the face of the dead individual. In a trade article on the state of embalming in 1921, Thomas Hurst identifies this important development, as well as situations in which these kinds of efforts should definitely not be pursued:

Demi-surgery is a name given the art of restoring mutilated features in accident cases, or in cases where a cancer has eaten part of the face away, or maybe a bullet or stab wound.... I have seen and done many wonderful things by resorting to demi-surgery, such as making a new upper lip, cutting out a cancer on the face and filling it in to match the other side, but if the head is crushed, nothing can be done and it is better that the body not be viewed.<sup>4</sup>

The principal aim of the artistic reconstruction? Hurst explains, “Proficiency in this field of endeavor will enable the mortician to improve one of his greatest services to the public, and that is the alleviation of grief.”<sup>5</sup> Funeral directors and embalmers understand their duties as a moral imperative with real therapeutic results: laying hands on the body of the dead for the relief of the human community is not only the basis for an economic transaction, it was also an ethical, religious duty that in their experiences eases the pain of those in mourning.

The chemical companies were particularly interested in successful embalming procedures: they were apparently confident that a natural-looking corpse would not only ease the suffering of the grieving family, but also be a potential source of good public relations with the local community who attend funerals and care about appearances. In one advertisement from 1928, for example, an embalming fluid company asks what becomes the key question of any self-respecting funeral director: “Shall the last picture become a comforting memory?”<sup>6</sup> This is indeed the crux of the matter. From early on, the industry was built on rhetorical and ritual links between the last look at the body, the creation of a “memory-image” or “memory picture,” the realization that death has occurred, and meaningful healing in the experience of death. The production of a memorable corpse, therefore, requires a delicate balance of capturing both life and death in the features of the departed: the funeral director must present a body

that simultaneously captures a living personality and forces the living to confront the fact of death.

One of the major fluid companies emphasizes the value of the embalmed body, and the weight it carries in local community relations, in a bulletin entitled “The Man of the Hour.” This bulletin, one of a series in the *Champion Expanding Encyclopedia of Mortuary Practice*, was published by the Department of Service and Research, a division of the Champion Company, and distributed to funeral homes throughout the states. It begins:

He is the dead man. Although his tongue be silenced, this is his hour. He may have been a timorous soul while here, but now he has become a hero.... He may have been a liar, but the message he speaks in death is true. Regardless of his character, he will have an audience. His audience will be small or large in proportion to his few or many friends. They will be impressed by the truth of what he is saying, and he is talking about *you*, to whom the duty of preparing his remains was entrusted.... You cannot refute his message if it is unfavorable to you. If he has praise for you, it is worth more than all the advertising space you can buy.<sup>7</sup>

The author goes on to imagine a scenario in which the customer is unsatisfied with the appearance of the body (with the body “speaking” to the audience, sending such messages as “Look at my swollen neck and cauliflower ears!”<sup>8</sup>). Positive word-of-mouth about the corpse after the funeral is clearly a critical element in the success or failure of a funeral home, according to this piece. If the skills of the embalmer allow the body to communicate to the audience, “I present to you a picture of me that is a true resemblance of my healthy, vigorous condition when we were so closely associated,” the rewards will come to both the funeral director, who will have an increase in business, and the mourners, whose memories will be sufficiently comforted by a last look. The author imagines the dead body saying to the living visitors: “Even though I have been dead for several days, there is no odor to remind you of unpleasant things. Such, indeed, is the memory of my appearance that I would have you carry, and this you owe to the man who was responsible for preparing my body for burial.... He realized that his greatest obligation was to present my remains, for a last view, in such a condition that my appearance at the time would alleviate some of your sorrow, rather than

increase it.”<sup>9</sup> Although others claim the funeral director’s “greatest obligation” is to the bottom line, the reality for many within the industry is that it refers to a higher calling.

Whatever the dead body may “say” to the living, the success or failure of embalming depends on the expertise and knowledge of the embalmer. Another educator and prolific writer within the funeral industry, Charles A. Renouard, son of educational pioneer Auguste Renouard, describes the difficult balance between technological intervention and preservation of natural characteristics. In his discussion of the science of embalming and the physiology of decay, it is evident that the embalmer is in a sobering battle with the forces of nature, forces that work at cross-purposes with preservation. In his 1940 article, “The Real Meaning of Embalming,” Renouard writes:

Modern embalming is a physico [sic] chemical proposition based on well defined cosmic influences that exert strange and relentless decomposition on everything that has served its earthly purpose. Nature exerts, without discrimination, that well balanced process of putrefaction, without which we would be overwhelmed with incalculable amounts of dead material on earth. While nature performs these exacting functions to reduce all dead organic material, we, as embalmers, must be just as exacting in our process of applying antiseptics and disinfectants to these organic substances to prevent nature from carrying out this universal process so necessary to our wellbeing [sic].<sup>10</sup>

While Renouard focuses on the scientific theories behind the embalming procedure, he does not fail to note the goal of modern embalming: making the body look natural for the mourners

Many individuals within the industry assume that their authority on the subject of embalming, an authority based on education, experience, and artistry, is enough to legitimate their professional standing in American society. Fortunately for the growing class of morticians, however, the undeniably strong demand by consumers from the beginning of the century for their services, and a presentable corpse, confirmed their own perceptions. A. O. Spriggs, who wrote a textbook on restorative art in 1946, explains that, “Perhaps one of the saddest human experiences is the necessity of committing a loved one to the earth without being

permitted to bestow a farewell look upon the features to be laid away forever.” Spriggs expresses some caution, like so many other writers do, about the limits of postmortem plastic surgery and paying attention to the wishes of the family when the face has been damaged beyond repair. He then argues that, although morticians should be circumspect about the use of restorative surgery, a growing demand, fueled by the public’s deep-rooted need to have a last look, requires that they remain proficient in these skills.<sup>11</sup>

In another textbook on embalming from the 1950s, *The Principles and Practice of Embalming*, the authors cover some of the reasons for embalming the dead. They begin with the practical, and scientifically obvious to them, issue of public health. After a discussion of the virtues of disinfecting the dead body, they turn to more religious and psychological concerns. It is self-evident to the authors that “funeral service is built entirely upon... a feeling of respect and reverence for the beloved dead.” Without these sentiments, they argue, the dead would simply be a “bit of refuse to be disposed of as quickly, easily and economically as possible.”<sup>12</sup> Because some Americans may have a less-than-reverential attitude toward the dead and the funeral, morticians feel a social responsibility to preserve the integrity of the dead, which in turn reinforces the integrity of their chosen profession:

Crudeness and disrespect have no more place in the presence of the dead than they have in the presence of the living.... Every student mortician must learn from his very first day of contact with this vocation that he must, throughout his entire professional career, regard every deceased person as a beloved parent or brother or sister.... The unnecessary exposure of any body, the admission of unauthorized persons into the preparation room, the regarding of the deceased as an object rather than as the sacred remains of a human being—these are crimes against decency.... We, the morticians of America, are the protectors of the modesty and dignity of the dead.... The care and disposition of the dead is, in all of its aspects, a religious rite which requires all of the dignity and solemnity accorded the other sacred customs and procedures of any church or religious group.<sup>13</sup>

<sup>6</sup> Advertisement, *Casket & Sunnyside*, v. 58, n. 8, April 15, 1928, 13.

Whether or not all funeral directors subscribed to the view expressed in this quotation and saw their duties in explicitly religious terms, by the middle of the twentieth century embalming the dead was a basic feature in American funerals. Before Jessica Mitford leveled her harsh and hilarious attack on the industry in *The American Way of Death*, embalming had already received its share of public criticism. Yet in spite of these highly publicized diatribes, undertakers continued to insist that the practice served a variety of purposes related to the public good, family unity, individual psychology, and, for sure, their own economic survival. From the pioneers to the present generation, embalming plays an absolutely vital role in the successful funeral service. What Mitford held up for ridicule, many within the industry, as well as many in the local communities that supported neighborhood funeral homes, understood as a socially significant, if not outright sacred, duty for the living.

If the only evidence for this position on embalming remained within the institutional literature of the industry, it would be easy to dismiss it as a form of propaganda. Other forms of popular support for this view, however, indicate that many outside of the industry prefer their dead be embalmed. The numerous letters and cards that funeral directors have received from their satisfied, and deeply appreciative, customers is a case in point. One of many examples reads:

Words are so inadequate to express my thanks and gratitude to you, for your kindness shown me and B—. “He was truly beautiful.” My prayers were long and many for a miracle that B— be found; and God saw fit to grant this. Then my prayers were for each of you in your work, that I might see B— once again, and *again He* granted another *miracle*.<sup>14</sup>

Without question, funeral directors and others within the industry also engaged in innovative rhetorical acrobatics that accounted for embalming in the lives of Americans: embalming was presented as a thoroughly modern practice, yet contiguous with certain American traditions; it was explained as a scientific procedure that also had religious and psychological benefits; and it was understood as a highly technical, hygienically beneficial intervention that required the delicate skills of an artist. But embalming could not have become the lifeblood of the industry if it did not satisfy some demand on the part of grieving consumers.

From the early years of the twentieth century to the final decades, the appearance of the dead, and the desire among the living for a memorable last look at the individual, has been a hallmark of the American way of death. Over the course of the century, many did not want, and were in fact outraged, at the inclusion of this practice in the treatment of the dead. But the success of an industry—a multibillion dollar industry by the 1970s—depended on, indeed was anchored by, the visible embalmed body. While the relatively minor successes of cremation, memorial and funeral societies, and do-it-yourself funerals must be acknowledged, and the evidence of questionable, if not outright illegal, activities by some within the industry must be admitted, embalming makes the prosperity of the industry possible. There are, of course, other reasons for this prosperity as well—but the embalmed body is squarely at the center of the cultural history of the funeral industry.

This presentation is excerpted from Laderman's *Death in Modern America: A Cultural History of the Funeral Home*, forthcoming in Fall 2002 from Oxford University Press.

### Notes

<sup>1</sup> Howard S. Eckels, "Can Embalming be Saved?" *The Sunnyside*, October 15, 1921, 1.

<sup>2</sup> A. O. Spriggs, *Champion Restorative Art* (Springfield, Ohio: The Champion Company, 1946), 18.

<sup>3</sup> C. F. Callaway, "Rebuilding Features—A Work of Art for the Embalmer," *The American Funeral Director*, v. 51, n. 8, August 1928, 60. For another example of this emphasis on what is "natural," see "How Do You Act?," *The Southern Funeral Director*, v. 17, n. 4, November 1927, 62.

<sup>4</sup> Thomas Hurst, "Embalming as Practiced Today," *The Casket*, v. 46, n. 7, July 1, 1921, 61. For a brief history of the changing terms, see Charles O. Dhonau and G. Joseph Prager, *Manual of Restorative Art* (Cincinnati, Ohio: The Embalming Book Company), 1932. Also see Howard S. Eckels' discussion of this procedure, *Derma Surgery* (Philadelphia: H. S. Eckels & Co., nd).

<sup>5</sup> Hurst, 21.

<sup>7</sup> “The Man of the Hour,” *Champion Expanding Encyclopedia of Mortuary Practices*, na, v. 2, n. 78, December 1936/January 1937, 309. Other titles in the series include “Massage the Trunk!”, “The Trocar,” and “Important Considerations for Summer.”

<sup>8</sup> *Ibid*, 309.

<sup>9</sup> *Ibid*, 311.

<sup>10</sup> Charles A. Renouard, “The Real Meaning of Embalming,” *Casket & Sunnyside*, v. 70, n. 7, July 1940, 40.

<sup>11</sup> Spriggs, 5, 8-9.

<sup>12</sup> Strub and Frederick, 4.

<sup>13</sup> *Ibid*, 5.

<sup>14</sup> F— Funeral Home, 1975 letter.

## Comment

**Jodi Halpern, M.D., Ph.D.**

**Joint Medical Program, University of California, Berkeley, San Francisco**

Tina suggested that I prepare about fifteen minutes of my own ideas on the topic, and then see how I could collect other people's thoughts together. But the truth is, I'm going to scrap everything I was going to say and just try to be completely spontaneous in terms of the kind of questions that I think these wonderful talks this morning have raised.

What I'd like to do is ask each of us here to think about two difficult questions. I'll say some things that I think integrate with these questions, and then maybe in the discussion, those questions, as well as many others, will come up.

The first question that the talks made me wonder about—and really, I have no answer to either of these questions—is: What do the dying need from others in the way of recognition; what form of recognition do the dying need? And the way to make the question really tough—for me, anyway—is to ask, in imagining my own dying, what would I want from others? Imagining the death of someone I love is not hard to imagine. Most of us here already are in a sense at the age of grief, where we've lost someone, and, of course, the talks today are very much about that. What do I think my loved ones would consider a fitting and appropriate recognition of their dying? I'm not talking about food, clothing, or shelter, not these things. And, specifically, I want to ask, do we want and need to be seen? That was the first thing, to be seen. A lot of my work is on trauma, on people talking about recovering and regenerating a sense of self in the face of the

loss of self and trauma. Primo Levi, speaking about the Holocaust, talks about a dream in which the most shaming and awful part of the experience, in the dream, is that the self he had become was not seen, that the survivor is unrecognized. And we know in the hospital, the dying patients are often ignored on medical rounds, not seen—people spend less time with people who are dying. We know that this whole conference, in a way, is motivated by a long tradition of covering up and not looking at death and dying.

There's a lot of literature in which people talk in terms of dying, in general, and then, in the trauma literature, about the need to be seen. But I would suggest to you that this is very controversial. And I'm not saying that we don't need photography because I'm incredibly moved by the role of photography. But photography is an art form; that's the point. And I would suggest, controversially, that we don't really want or need, necessarily—and I know people may disagree with this—just to be seen in the most objective sense, to be photographed in that sense, or to be visually, from a bird's-eye view, seen in the state of our most utter helplessness and suffering. And I think that Jim's work very richly addresses that ambivalence about being seen. I thought it was very important when he showed us the woman who said to him, "I'd like to see a picture of you close-up when you're 76," suggesting that there's a shame in being seen in a certain way. Of course, most of his pictures are not, including that one, close-ups; they are depictions, presentations, and the use of language is beautiful there, of subjectivity in a person. So they're not just, in any sense, a kind of bird's-eye objective picture of dying and death.

But the survivor literature in trauma, especially the Holocaust survivor literature, often makes it sound as if what people want is that other people see what happened. I think when we're thinking about dying, that's a major question for us: Do we want people to see? Do we want them to see us at the moments that we tend to look away? And do we want our loved ones to see?

Sandra's very beautiful and very sad description of what is clearly a very traumatic moment, "a body I had loved turned into a dead thing," presents another reason why I would say that there are things to be seen, but not necessarily just what is unmediated by art. So we have a triad: art, mediation and seeing.

Do we want to be heard? What is it that we want to be heard? I think

there's a real ambivalence about talking when people are dying. I'm just finishing my first book, on empathy in medicine and doctor-patient communication. I'm really addressing empathy in terms of physicians though other people here, like Patricia Benner, have explored it in nursing, social work and other areas. In writing my book, I came to realize that the cases that I picked were all people who got furious at me for trying to hear and communicate verbally with them at a time where they were dying. I can't do a whole case in the time I have here, but my book is really focused on a woman who was refusing treatment. She was a diabetic woman in her early 50s, who had come to the hospital for her second above-the-knee amputation from vascular disease. And she had gone through the surgery, a planned surgery, and she had done fine before, after such a surgery, but she would now be wheelchair-dependent. That was known when she came in. But suddenly, in the hospital after the surgery, she stopped communicating. No amount of morphine would alleviate her pain, and she said that she wanted to stop dialysis and to die. And the whole treatment team had all sorts of reactions to it.

I was in my very first week of training as a psychiatry resident, completely green, and everybody else was frantic—a medical ethicist, a surgeon, an internist, a psychiatry attending—and she told everybody, “I know that without dialysis I will die, but I don't want to live my life. I've decided I don't want to live a life in a wheelchair. I don't want to be living a life where I'll be on dialysis three days a week. I just don't want to go on; I'm having too much pain.” Then, because I had suspicions, I said, “Is there anything besides your body that's hurting you?” And she wound up telling me that her husband of twenty-five years had told her while she was in the hospital that he was leaving her, that he could never live with anyone as disfigured as she was. And she started to cry as she told me about it. And then she turned to me—and my whole career for the past ten years has been influenced by this experience—she basically started to yell at me, really yell at me, so that I thought she was going to throw something. I was worried she would just hurt herself because she was so upset. And she said, “Your asking me to talk about this is the cruelest thing that anyone has ever done to me. Get out of here!” And she continued to scream, “Get out of here!” And this is after I had built up a rapport, where she had been more comfortable with me than anybody else on the team.

And I went out of the room, and a lot of other things happened.

Unfortunately, the medical ethicist and psychiatrist and surgeon and internist all agreed that she knew the risks and benefits of treatment and non-treatment, and had the right to make the decision that she was in too much pain from her post-surgery pain, and wasn't going to have dialysis. And they basically turned up the morphine and she died. I never got to talk with her again.

This was an extremely influential experience for me. But one of the things that I have thought about, subsequently, is her saying that making her think and talk about this was the cruelest thing anyone had ever done. Now after dealing with many other cases, I'm convinced that that's usually the beginning of a therapeutic alliance. In other words, I think she was furious at her husband, for an obviously good reason. I don't think she felt willing to tell anybody what was going on. And I think there was the potential, if I had been able to see her more, that something would have happened. But she really did say to me, "Why do I have to think about this before I die? Why do I have to get into my head? Why do I have to have a conversation?"

So that's the first set of questions, and they have to do with the issue: What do we want? And I would suggest we do need a kind of acknowledgment. When we imagine our own dying, there is something we want. We want some form of acknowledgment, some form of recognition. You've seen, in both Jim and Sandra's work, some modeling of what that acknowledgment and recognition using art might involve. And so I'm hoping we can talk about that.

The second question that I hope we can talk about was really posed by Sandra's very important observation that in the literary examples it's the dead who mourn and grieve the most. Now, that is really interesting. Why is it the dead who do the mourning and grieving in the most exquisite and intense way? My connection with that, again, came from the work I've done on trauma. I want to cite philosopher Susan Bryson, who survived a rape and a near-death assault. She describes how rape survivors, who have tremendous difficulty recovering a sense of self in the face of trauma, can't empathize with themselves, but then sometimes in groups, in survivor groups, they can listen to the narrative story of someone else in the group and empathize with that person and, therefore, begin to empathize with themselves. So Bryson writes:

The fact that survivors gain the ability to reconnect with their

former selves by empathizing with others who have experienced similar traumas, suggests that we can exist only and primarily in connection with others. It also suggests that healing from trauma takes place through a kind of splitting off of the traumatized self, with which one then is able to empathize, just as one empathizes with others. The loss of a trauma survivor's former self is typically described by analogy to the loss of a beloved other. And yet in grieving for a dying other or a dead other, one often says, "It is as though a part of myself has died." It is not clear whether this circular comparison is a case of language failing, or, on the contrary, revealing a deep truth about selfhood and connectedness, but the essential point is that by finding some aspects of one's lost self in another person, one can manage to a greater or lesser degree to reconnect with it, and to reintegrate one's various selves into a coherent personality.

In thinking about why it is that we, in a certain sense, project our grieving onto the dead, it seems very important that we think about this lack of direct access to the experience of loss, and the need to mediate loss indirectly through our empathic connections with others. And, actually, the quote I just read you by Susan Bryson, to me, parallels in its logic Sandra's quote, which is, "If those who have died are still part of us, then death is part of us too." Then we can somehow mediate in our ongoing selves that unselfing, that primarily unselfing experience of death.

So in thinking about what we need, I've suggested not just to be seen, not just to be heard—we're ambivalent about those things—but there is this kind of acknowledgment that art talks about. I think it's extremely interesting to think about the tradition of embalming, and how important it is for people to be seen as beautiful in some way. It's easy to be critical of that, but it's also very interesting to think about how different it is to need to have the dead do our mourning, in which case we really are using our fantasy, our imagination of connection with the dead, as a way of empathizing, rather than starkly seeing our loss. Of course, we may not always love the dead, but I'm suggesting that that bestowal of meaning,

through projection, through empathy, allows us to take something back in. In a sense that is not necessarily a beautification, but it is an aesthetic and emotional transformation, rather than a stark recognition. And so, is it that different or that hard to understand why the American public, in general, need to see an embalmed face restored, a disfigured face restored? I mean, it's very interesting to think about the meaning of that kind of restoration.

One last thought connecting all this that also comes from this question of putting a face on death and recognition and empathy. This was prompted by Jim's slide from his first book, where the woman has lost so much, but says, "I still have my dreams." The question I'm still trying to address is what do the dead, the dying need acknowledged? "I still have my dreams," she wants people to know, "I still have my dreams."

So regarding this whole issue of realism, of stark reality versus art, of art that beautifies, and in a sense both "embalms" and beautifies, is this all that we're doing here today? I mean, what do we do with art? Are we covering up? Are we emphasizing? Are we making a connection? One thought I had about this is that people talk about the loss of a narrative of self. But I think I would shift the terms to say that what we're trying to do with art here, today, is to narrate a loss of self. And there's still a narration involved, there's still a story.

Ultimately, despite all our metaphors, and despite the fact that we describe in the literary imagination the dead grieving and calling us back, I would say that dying ends a conversation; and sometimes, just as soon as people know they're dying, they want to end the conversation. And there is a way in which we never do hear back something very critical—whatever we do know or hear or think about—we never hear their response to that. Nothing new can happen from them in regard to how we've dealt with their death. We never get feedback.

And so I want to suggest that the kind of acknowledgment that's needed is an acknowledgment that holds somehow to the meaning. As Jim's work shows, it's not his father's death, it's the meaning of his father's living *and* dying that continues on. And through art we do hold on to the meaning of people, which is very different from having an ongoing conversation with them.

**Session One:**  
**Silence, Art and Ritual**  
**Discussion**

CHRISTINA GILLIS: Do the members of the panel want to respond to one another, or to Jodi at this point?

SANDRA GILBERT: I'll make one comment which, though it's still half-formed in my mind, focuses on this issue of looking and seeing. I begin with the idea that we now inhabit a death-denying society. At least—and some people have actually argued that point with me just in the last week—I think we inhabit a death-denying society. Hence I think that any looking, any ritual, any confrontation with death that we can make happen is useful, including the rituals of embalming that we are used to thinking of—as in Jessica Mitford's work—very sardonically.

I'll add one other note on a very controversial point: I think that Mitford's book, *The American Way of Death*, which was just recycled in a new version, is problematic because it too, in a way, is a death-denying book. She said somewhere that funerals are just a lot of nonsense and that we ought to get rid of all of that; we ought to just sort of get together and sing a few songs and then shovel the dead person into the ground. But this may be just another form of shoveling death into the ground. So I guess I'll just say that anything we can do—looking, acknowledging, in some sense honoring the existence of death—is important.

JIM GOLDBERG: With my father's death I was there. I was the son and the photographer, videographer. I was there simultaneously in many roles. Since I saw him die, seeing him dead was just the extension of the moments before he died.

With my mom, the death was unexpected, and when I got there, she was at the funeral home in the crematorium area. And that, in itself, is a somewhat bizarre place. There were other bodies stacked up in boxes, and there were guys smoking, and there were guard dogs barking. So there was this whole environment of the business of death. And it was very hard for me to photograph her.

Perhaps the difficulty really was that I wasn't there at that moment of my mother's death. And, maybe, as a recorder of memory—and that's what photographers or artists often are—you have to be there during the act. To see my mother dead was very hard. She did not look good. This is not an argument for embalming, but as an artist, seeing her was for me hard to record. I showed you one image that is quite beautiful, but it's more metaphorical, not like the literal image of my father and the watch where we see the moment of his dying. I have much more literal pictures of my dad dying that are shocking even for me to look at.

So of all these pictures that I had taken of my mom, no one wanted to see them. And I don't know if it was because of a denial of death or because they're ugly. Maybe it's a rhetorical question: Why do we look at these things? What is the need of seeing? Or can words sometimes, or pictures that aren't so literal, or imagery that isn't so literal, take the place of actually hitting people over the head with the facts? But sometimes documentary people show so much that we already know that we can ask why we need to see it.

GARY LADERMAN: I want to hear from others. But I very quickly realized in doing the research for my book [on the development of the undertaking profession] that I'm definitely taking on the denial thesis and saying it's misguided and off the mark, particularly for the period of the first half of the twentieth century. I'm finding all kinds of evidence that speaks not to denial, but to obsessions with the topic of death and the return of the dead. That is what my work on Disney is about, all these early, crazy Walt Disney films that are not so crazy. The death of Bambi's mother is probably firmly emblazoned on most of our minds, in terms of our experiences with death. Maybe we could talk a little bit more about that. The denial thesis is particularly identified with that first half of the twentieth century. It's interesting to think about it too in contemporary

culture, where the highest-grossing films deal with the encounter with death and the return of the dead: *Sixth Sense*, *Ghost*, even *American Beauty*. It's like *we* are the dead. I was hoping I'd get a chance to say that.

TOM COLE: I'm Tom Cole from the Center for Medical Humanities at the University of Texas in Galveston. I'm not so sure that I would agree that dying ends a conversation. A lot of what I was picking up from Sandra—her meditations, personal narrative—was something along the line that death ends the chance of a better relationship, but that it's absolutely essential for the living to make meaning and to come to terms with and memorialize and reword those relationships as long as they are alive. Perhaps the old idea of the denial of death just meant the denial of death as if it were some kind of external reality that's out there in the world. But we all know that that's not true, that death is as much a fact of our imaginations as it is of any existential or objective reality.

So keeping the conversation going, I think, is really essential. When I was really moved by Jim's photographs, I was really struggling with, "How are you doing this? How can you put your watch right here while your father has just died in the background? And how can you be the photographer, and the son, and the experiencer? What is this for you?" Jodi asks what the dying need, but I think the question should also be about what survivors need. We have to tend to both of those questions, I think, to make more headway on the denial thesis.

SARAH LIU: Sarah Liu, Department of English, UC Berkeley. My question deals with an individual dying, and how different individuals will do different things. It seems to me that in some ways we are a culture obsessed with death, but obsessed with producing the idealized death. For example, this *Tuesdays With Morrie* book. I thought it was wonderful that Morrie got to die in such a nice way. He was coping, he was humorous, he made dying easy with his family, so on and so forth. And yet our culture's celebration of this type of death implies that there's a good death versus a bad death. And that if you're dying, and you're bitching and moaning all the time, and you're complaining, or if you don't want to talk, you don't want to open up, somehow you're not doing it right, you're not dying well.

CHRISTINA GILLIS: So in other words, Morrie really did get to "make the last

presentation”?

SARAH LIU: He died on his own terms, which is fine. But having his terms apply to everyone else seems wrong. And so maybe what the dead want is to be seen as individuals, not as examples of “there is one way to die and this is it.”

GARY LADERMAN: Speaking of burials in the contemporary period—although I haven’t really gotten there yet in my book, I think that what we’ve seen in the past few decades is an increasing effort to personalize and customize funerals, so that they reflect individual traits. This is different from the first half of the twentieth century, where funerals were pretty uniform. So, again, all this is historically contingent. There are cultural scripts about the good death that every culture has, and these set up perhaps an idealized image that can lead to a lot of disappointment or confusion.

CHRISTINE FINN: I’m an archaeologist, and I’ve had the experience of discovering, disposing and dismantling bodies, or skeletons, which is a very profound experience in itself. But what I’m deeply interested in at the moment is accidental embalming. I’m looking at 2,000-year-old bog bodies that have been found in Northern Europe. I put some photographs up on the board outside, taken by a photographer in his role as archeological photographer of a museum. He took them, really, as pictures of record. But what happened to the photographs is that they’re playing a role in a different kind of dialogue, one that has been picked up by the poet Seamus Heaney, amongst others, and various artists and sculptors and filmmakers whom I’ve been speaking with.

When I show these images at lectures, depending upon whom I’m speaking to, I get very different responses. If the people are attached to the artistic community—poets, writers, artists, filmmakers—they say, “Wow, how amazing, we can look at a face that’s 2,000 years old and it looks like someone I know.” I think those in the more scientific community become a bit more reluctant; people stand back and say, “I don’t get that, I don’t like that, I don’t like that image.”

SANDRA GILBERT: What do they mean when they say, “I don’t like that

image?” Does that mean they don’t want to look at it, they find it disturbing?

CRISTINE FINN: They find it disturbing instead of moving. It’s as if it’s not in the right context. What they see is a forensic piece of evidence that’s being shown in a lecture which includes poetry and art.

SANDRA GILBERT: I guess this brings me back to the whole issue of death-denial in our culture. That we make lots of movies about the dead coming back is not to say that we aren’t a death-denying society. It’s precisely to say that we are. We have movies in which Mickey Mouse is run over by a truck, but he jumps up again and there he is.

What’s interesting is that there’s a tension between the arts, poetry, certainly, as I see it now, and the culture that makes movies about dead people coming back; between people who want to look at pretty images of dead people, and poets who want to talk about real particulars, who want to testify or bear witness to the real particulars of death and dying, or who want to take photographs, or who want to uncover the secrets of the medicalized death and make art out of them. And it seems to be that for a contemporary poet, death is the kind of dirty secret that’s being outed from the cultural unconscious, you know, like sex. We all talk about sex now, but we do have trouble with death as the actual, the sort of documentary details of death, or the vision of the person as a particular person.

CHRISTINA GILLIS: Gary, do you want to make any comment on that ?

GARY LADERMAN: Well, my position there is that the death-denial thesis doesn’t get the whole story. It’s partially true, definitely, but there’s more going on than just denial. As you were saying, this kind of a generalized comment doesn’t capture the nuances of what I think are the cultural expressions of obsessions with death.

CHRISTINA GILLIS: Anyone else on the panel want to respond to that?

PARTICIPANT: I would also like to get back to the original question that was

posed about what does dying mean? We've gone around it, but haven't addressed it as much. I think Jim's photographs were fabulous, from his father's point of view. You saw two sides of it. You saw Jim responding; he desperately wanted to get his father in the chair, which is what his father wanted; and you saw his mother, who desperately wanted his father to live. What do the dying need? I haven't heard, and I want to hear more about that.

CHRISTINA GILLIS: Let's open that up to everybody.

GWEN ANDERSON: My name is Gwen Anderson from the Stanford University Center for Biomedical Ethics. And I think my comment will relate to that. I want to take us back to the images of the people in the nursing home, specifically, some of their comments that help us to realize our assumption that life is so precious, that we do want to have life right to the very end. Some of those comments helped us to see that life is not that precious to everyone, and, in fact, there is death within the living, and that there is a living that is preparatory for death. What is it that we could possibly help those people with? Their comments are not something that we necessarily want to hear. So how we facilitate or how we shut down that conversation I think is particularly important for us to think about. And Jim's photographs—and the combination of the photographs and comments—show us where the person is at in his or her life, and draw our attention to the fact that there is dying and living in the process of dying. And for those who voice the need that they don't necessarily want to live anymore, how can we possibly help them toward that dying?

JODI HALPERN: I just want to say one thing because I think that is an important question. Thinking about death and dying, in light of thinking about people who have suffered traumatic losses, suggested to me that the risk of shame, which has come up in different places, is very important. So that at the very least, whatever else is involved, it seems that to be seen in a kind of objective cold way, visually, could be shaming. But that is not of course what I see in Jim's photography. Also, part of our thinking about this issue of the choices beyond just extending life at all costs has to do with this issue of the acknowledgment of the

self that has lived and that is meaningful, that hasn't been destroyed as a self.

GWEN ANDERSON: I think it's part of the integrity of self and the wholeness of self. And even though it may appear that life is not worth living, or that that person wants to move toward death, that in and of itself is part of the integrity. And we want to respect, value, honor and celebrate that.

MAURITA GRUDSON: I'm Maurita Grudzen, Stanford School of Medicine, and also Pacific Lutheran Seminary. In seeing your images of the nursing home and reading the quotes following up, I thought of the people who need to be there as caretakers. They need to be people who can hear the integrity, which it seems is the essence of spirituality, and also can see the beauty that is in the wholeness right there. There's the ugliness, but there's the beauty, the beauty of the soul. And I couldn't help but flip back many centuries to the first hostels and hospices that were in the context of monasteries. I also come out of that experience. So I ask, what kind of training do we need to provide to be attuned to that spiritual self, which is beyond religion?

BETTY DAVIES: My name is Betty Davies, and I'm from the School of Nursing at UCSF. My comment has to do with your question about what it is that the dying need. And I certainly don't claim to have the answer to that, but one of my thoughts is that I believe, based on my experience and my research, that it's not so much death that people fear oftentimes, it's the dying. And it's the process of dying that your photographs portray that sometimes can be so painful and so ugly, and is not beautiful always. I think in our society that sometimes we fear or we avoid anything that is ugly. I'm not sure we're obsessed with death; I think we're obsessed with beauty, the beautification of things. And so when people are dying, they become ugly in a physical sense, they become helpless, they suffer. And when people are grieving, they become ugly, physically ugly—their faces contort, they feel the pain, and they express that pain. And we want to avoid that discomfort and that ugliness that's just part of life. We talk about death and maybe to accept death is part of life. But I think we need to accept ugliness as part of life, that that's how it is, and we're not always happy and beautiful, and we cannot be. And so your work, I think, portrays some of that ugliness. And when people are old and

helpless and ill and ugly, what it seems to me they need is someone who can overlook that, somehow to deal with the repulsion that we feel when we see that, and still be there.

JOHN GILLIS: John Gillis, grateful spouse. I think what Ms. Davies just said is really quite profound because it struck me, in all the talks, that we're really dying as we live. I was struggling to find the insight that you just provided, that is, that virtually all our life rituals are built around idealizations, that we're always prettying up life, whether it be at birth, at birthdays, at weddings and so on. The ugly parts of our lives we have found no medium to portray. We don't photograph divorce proceedings; we don't, as far as I know, ritualize the ugly moments in our lives. So this is not a plea, somehow, for the beautification of those ugly events, quite the contrary. It would be to find some aesthetic that does not rely on beauty alone, but honestly confronts and represents, say, through photography or poetry, that which in our day-to-day lives we're not facing either. We're very practiced at this perfectionism, at this idealization. And it's not at all surprising to find the the end of life so problematic.

JOHANNA WEINBERG: Johanna Weinberg, UCSF. It struck me that we've spent a good part of the last part of the twentieth century talking about autonomy and patient autonomy. And it became so clear, Jodi, when you were talking about this experience that you had, that it almost could have gone either way. That is, you know, the patient tells you about this terrible thing that's happened, and, in some ways, you could say, "Well, she's deeply depressed and she shouldn't be allowed to give up treatment if she's so depressed because that could be treated." The doctors who come in don't see that side of it; they simply see, "We must let her live as an autonomous being." Their way is one that we've developed to cope with some deaths. We say, "All right, it's autonomy." We are giving the individual autonomy, but we haven't really been able to balance that with the need also to give what the family or the rest of society needs in terms of the coping process. And I think that the combination of the technology that's available and this tremendous assertion of individual autonomy has made it in some ways more difficult for us to understand what death is about.

JODI HALPERN: That's a very important point, and I would argue that we

don't really know what we mean by autonomy by itself. Because if the conditions for autonomy, even in philosophers like Kant, have to do with being able to imagine your future, my argument is you can't imagine it. For someone who's dying in Hospice, it's a very immediate future that becomes bearable or tolerable. I want to emphasize that compassion, relationality—those are conditions for exercising autonomy.

TONY BARKER: I'm Tony Barker, an oncologist from the University of Washington. And I wanted also to respond to this last thread in our discussion. I mean, your question about what the dying need is a really profound one, and in the story that you told, I was really struck by the parallels of all that to the trauma survivors, who have, you know, lost a part of themselves and are really struggling to regain that. I see the same kind of thing. I've been interviewing people who are really seriously pursuing physician-assisted suicide, and you see some of the same issues for some of them, who have to think in terms of reconstructing a new self that isn't based on having a beautiful body, a fabulous career and so on. And some people can do it—maybe Morrie, for instance—and other people just decide they can't, and they decide that this is the end of it.

I'm also thinking of Jim's photograph where the guy said, "I'm all gone." We actually have interviewed people like that in our study, who have really felt as if their selves were destroyed in such a way that they were just not recoverable. And they really were at the end of their lives, and some of them actually had what their families considered a wonderful death. So it's all a challenge.

The other part of that question that I think I wanted to bring up raises the issue of what we need from the dying. If we're going to ask what the dying need from us, the thing that comes up is what *we* need. Some of the comments, I think, have reflected what we as other people in that conversation need.

CHRISTINA GILLIS: I think we have time for maybe one more question. I hate to cut this off, but I'm sure we will revisit these questions.

ALEX McCLOUD: I'm Alex McCloud from the California Institute of Integral Studies, and I've come here as an artist and someone with an interest in aesthetics. And now I have a couple of comments. One is this question of beauty. Having

recently read Elaine Scarry's *On Beauty and Being Just*, I think, actually, that the issue is the kind of cultural imperialism that we may put into beauty. If, for example, we create the ideal "good death," then everything else becomes scaled against it.

My other question concerns Dr. Halpern's second point, which intrigued me because it had implicit in it a question about what the existential status of the dead is. You spoke about how the conversation ends. And yet in Dr. Gilbert's comment, I heard very much about the presence and the continuation of that conversation. And it strikes me that what we may imagine the existence of the dead to be, as well as the nature of our spiritual beliefs and personal experiences, would very much affect how we would engage this question. You spoke about projecting our feelings onto the dead; I might say we should talk to them. It seems to me that was an unspoken assumption that we might not all share. And I don't know how that might affect the conversation.

JODI HALPERN: I'm very glad you said that, because in no way was I trying to foreclose these various models, just to suggest the thought that provokes me, which is that we never get to hear back in a certain sense.

CHRISTINA GILLIS: Nor am I ending this conversation. We're coming back, and there is a lot more to talk about. I want to thank the panel and all of you for a wonderful morning.

Session Two

# Time—Counting the Moments/ Making Moments Count





# Editor's Note

## Session Two

In Session II, chaired by Gayle Greene, Professor of English at Scripps College, we turn to time: to “final moments,” to evaluating and identifying the time of dying. As physician Guy Micco’s comments suggest, identifying the moment of death becomes inextricably bound to the question, what is death? And central to this vexed area is the role of technology. In various ways the panelists confront the question of how technological innovation in medicine has changed our conceptions of the boundary between life and death.

Oncologist Debu Tripathy begins the session with a consideration of a paradox that haunts both physicians and their patients: new technologies may actually hold out promise for some patients but also create false hopes in a culture that craves certainty and sees technology as the means of attaining it. Such a paradox, Dr. Tripathy argues, suggests that medical practice should include talking with patients about the limits of medicine and, in some cases, the possibility of their dying of their cancer. In a sense, Dr. Tripathy is talking in a medical context about “preparation,” a notion that literary scholar Michael Witmore explores further through its religious connotations in the literature of the early modern period that he studies. Particularly concerned with conceptions of accident, Witmore evaluates earlier generations’ abhorrence of a sudden death that precludes preparation for the journey beyond. With reference to the ghost in Shakespeare’s *Hamlet*, Professor Witmore emphasizes the significance of the voice

that speaks from oblivion, from an “unknown country.” He suggests that contemporary fascination with the “black box,” the airplane voice recorder that is intended to help tell the story of the air accident in the event of a crash, is evidence that the “suddenness of death has retained its full measure of power.”

Looking at time and death in another way, physician and bioethicist Larry Schneiderman argues for a realignment of time and nature. We go against “nature,” Dr. Schneiderman argues, when we rely on technologies to prolong lives such as those in persistent vegetative state. It is, in his view, simply “hubris” not to recognize our “mortal limits.” As both commentator and presenter, physician Guy Micco counters Lawrence Schneiderman’s equation of “life” and “personhood” and then, through the anecdote of Mr. Reggie, explains the complexity of the question “when is dying?” Dr. Micco ends his comments with a clip from Fred Wiseman’s classic documentary film of death in a hospital, leaving us with Wiseman’s powerful image of the physician’s ear turned to the body, listening for the heart’s final beat.

The discussion that follows the presentations in Session II returns to issues in medical care, particularly the inadequate training of physicians in dealing with patients who are diagnosed with life-threatening illness. As in our other sessions, comments fall into two general camps: those who see death as a human passage and those who view it as a physiological event. Historian Tom Cole provides the final comment of the day, pointing out that we cannot find universal abstract answers to this dichotomy, that we must use “experiential terms that are moderated by metaphor and language.” —CMG

**Debu Tripathy, M.D.**  
**Oncologist, University of California, San Francisco**

I'm a medical oncologist at UCSF, and my investigative work has been in the development of new therapies for breast cancer, primarily for advanced breast cancer. This provides a good platform for my talk to you today and also for discussion later on this afternoon. I want to speak about the paradox that emerges when we have in our hands new and exciting technology with benefits that may actually be somewhat limited, but which are presented in dramatic ways to the public; and how this paradox comes into sharp relief when individuals seeking new therapies and new technology for an incurable cancer have to confront the notion of mortality and the fact that, despite advances in technology, they may face a situation from which they cannot benefit.

The last few years have actually seen a scientific trend towards a difference in the way in which we look at cancer. Number one—and I'll focus my comments on breast cancer, since that's the area from which I can provide examples—in the area of prevention, there have been some advances in which small benefits in lowering the risk of getting breast cancer have been achieved with drugs that themselves have side effects. And that, of course, has generated a lot of controversy. For the majority of women in this country and in most industrialized countries, the mortality from breast cancer is actually very good: only a quarter of patients will actually die. And that is because the patients' symptoms present at earlier stages, mostly through public awareness, through mammographic screening. And there have been advances where therapies after surgery can clearly improve the long-term outcome of individuals. But this improvement in outcome

is more of a statistical finding. In other words, when you study one population getting a therapy compared to a population that is not, you see improvements in outcome. But it's very difficult to point to an individual person and say, "For you, this therapy is going to work." You're basically lowering the risk, which is a very difficult benefit for many individuals to perceive and comprehend. And then, finally, in the area of metastatic breast cancer, a disease that is generally not curable and generally does lead to death, there have for the first time now been new therapies that can improve the long-term survival of patients. These are not curative therapies, but they are therapies that can extend life.

Having described that as a backdrop, let me talk now about some of the struggles that individuals have, and where I think technology has brought us in that regard.

When someone comes to you for care, especially as a sub-specialist, someone who is doing research, someone who is at a referral center, the expectations are quite high. And we have become a culture of technology, a culture of high expectation. And why not? If one looks at computer technology and communication technology, we have made great strides. We now expect to be able to travel to Europe and check our e-mail daily and get on the phone and talk to whomever we want any time of the day or night. And the same thing has happened in medicine, although the implications for longevity are a little more blurred. As I have mentioned already, in the area of breast cancer these benefits get a lot of press, and they are presented as the triumph of technology over nature.

There are many reasons for that hyperbolic presentation of science. Part of it is that we are used to success; we like to present success. It sells newspapers better. The *20/20* show is appealing to watch when it puts a technological advancement into the perspective of a human individual, showing us a very dramatic story of someone who responded to a new therapy. In reality, it may be the case that the chances of response might only be 20% and treatment may only prolong life by a few months, though the news story is certainly not transmitted that way to the public.

So one of the challenges for us is how to convert that expectation of technology's success into the reality of what we can do for an individual patient. In terms of how we as oncologists can interact with patients, many limitations have emerged over the years and for many reasons. I'll enumerate some of them.

One was illustrated pretty well by Judith Light in the play *Wit*. The play is about a woman's struggle with terminal cancer, and it portrays the medical profession and medical oncologists, in general, as very cold and uncaring. While one can interpret that in many ways, I think that the play calls attention to many limitations that medicine has today, not just the uncaring nature of some practitioners, but the limitations that oncologists and other care providers have in dealing with their patients.

Time is probably the most important element that is missing. And this, again, is what creates the gap that I'm describing between the expectations and what can be done. When I see a patient in our practice, there's a certain amount of education that needs to be done—in fact, quite a bit. In this day and age, the availability of the Internet, and all the books and periodicals that are out there, help get information out to patients, but they also hurt the situation in that the information is not being filtered and hence can be to some extent misleading, conflicting and confusing. The limitation of time that is available to us to educate a patient about the technology applicable to their particular situation is a problem that limits our ability, over time, to navigate a patient. Just as you would steer a very large barge down a river, making very gentle turns slowly, in order to achieve the direction you are looking for over a long period of time, we need to proceed in very slow, deliberate, but strong moves. Time does not always allow for this.

The process of educating someone about new technology is something that I undertake early on. After all, as I mentioned, people are coming to understand what new technology has to offer them. But in discussing the technology, they must also understand that, for each person, the situation is going to be unique. And it's in that uniqueness that one starts to discover what the limitations of therapy are.

The final item that complicates things is a general uncertainty. Cancer and many medical illnesses are very heterogeneous diseases, they present in many different ways, they have many different natural outcomes, and they respond to treatment differently. We know from a molecular standpoint that breast cancer is genetically very complex, and therein lies the individuality of the therapy. We can portray to someone what the technology we have to offer them is, what their particular situation is, and what the expectations of therapy might be, but it is all shrouded in levels of uncertainty. "Here is a new monoclonal antibody that will

bind this ONCA gene that can regress your cancer. However, only about 20% of individuals with your particular cancer respond. One of the ways we will track this response is by measuring scans and doing blood work, and then making decisions as time goes on.” These are the lines that a patient might hear. But these lines contain several messages. Number one is “You have a serious problem.” Number two is “I can help you.” Number three is “We have new modern technology that can be a benefit.” But the last point is “We don’t know how you’re going to do.” Uncertainty. Confronting mortality and death tends to be one of the more final facets that one might bring up. I think that’s inappropriate, I think that one has to be able to bring up mortality.

At our center, we are exploring a model where, in the initial consultation, not only do we try to take a very holistic approach in assessing their medical situation, their social support, and their psychological well-being, but we start to bring up these issues at the very beginning. I’m a little nervous about this. This is not an area in which there is background science to guide us, where there have been any studies to know what the impact will be of bringing up mortality very early on in someone’s process of interacting with our center. Even if they have early-stage breast cancer and their chances of dying from cancer are small, we think we need to bring it up, but much more so, when they come to us with advanced breast cancer. When we’re still taking a very aggressive tack in looking at what their options are and proceeding with aggressive therapy before we make a decision as to whether this is working, it is very difficult in the same day and in the same session to bring up the prospects of failure and the prospects of death. Nevertheless, our belief is that we need to approach it in a way that is positive, yet starts to get those issues in at the very beginning.

I look to comments from my colleagues today in the discussions that follow to help refine the directions that we take with this whole process. I think we can achieve a synthesis of emerging technology, high expectations, and, at the same time, acceptance of mortality and acceptance of dying. It seems as though these are opposing forces, that they cannot be mixed and cannot be taken well together in a given patient and in a given session; but I do think there is a way that we can bring them together. And I hope, in the future, that I can present to you what we are seeing, at least from a qualitative standpoint, in this integrated approach to patient education and care.

**Michael Witmore, Ph.D.**  
Department of English, Carnegie Mellon University

Today, I'm going to talk not so much about technologies that preserve life, but technologies that preserve memory in the words of the dead.

I'm going to talk about *Hamlet*. *Hamlet* is the focus of the book I'm writing on accidents and accidental death in the sixteenth and seventeenth centuries in England. And the theme of my talk is going to be suddenness. I want to talk about accidental death that offers the opportunity for one to disappear in consciousness immediately, without premeditation; and I want to look at what the particular fear of suddenness might be, the degree to which we share it today, and the way in which it animated early modern discussions of death.

I'll start with a book that I saw reviewed about a year ago, while I was writing a chapter on *Hamlet*. It's entitled *The Black Box*, and it's edited by Malcolm McPherson. This book contains transcriptions from flight data recorders of airliners that have crashed. The descriptions are arranged in sequential order. There's very little narrative provided; all we have from these "black boxes" are conversations between pilot, copilot, sometimes the crew, and the tower. The book is unsettling because it gives us a transcript or a recording of a moment that somehow promises to reveal a mystery, the mystery of what one thinks and does in the last moments of life. Some of these descriptions are absolutely flat-footed—we have technical discussions of altitude, tactical decisions about whether to land, whether to circle. Once in a while, a pilot will realize that he's going to crash and will say something to a loved one. The recording will end with, "I love you, Amy," or it will simply be cut off.

I think these recordings are an artifact of our own interest in death, and our attempt to understand it using technology. In a way, the black box is like a passive observer that survives the encounter with death. It speaks when the bodies are no longer there to speak. It survives a fatal crash. It submits voices to an audience that has already anticipated it. Why put the box in the airplane in the first place? Because you expect that someday you'll need it. So the addressee is anonymous; the messages are usually there for their evidentiary value, telling us what may have happened in the last moments of a particular flight.

I became interested in this particular book because I was thinking about the voice of the ghost in *Hamlet*, about what that voice brings by way of memory to the son, whose father has been famously dispatched while sleeping in the garden, about the way that voice can speak to the living, even though it has no body. I think the ghost would have been intriguing to early modern spectators precisely because it didn't have a body, yet somehow memory is transmitted even if you don't have a material link to the person who is dead. The ghost, in effect, reveals the secret of what happened to Hamlet's father, and it's that secret that sets the plot in motion.

The play itself focuses studiously on moments of ending, the endings of life. For example, when Hamlet gets the letter that Claudius has written to the King of England, describing his plan to put Hamlet to death, he rewrites it for Rosencrantz and Guildenstern, and instructs the king that "...on the view and knowing of these contents, without debatement further, more or less, he should put the bearers to sudden death, not shriving time allowed." That phrase, "not shriving time," is important because it suggests that Hamlet wants to preempt an ending for Rosencrantz and Guildenstern and specifically make it impossible for them to make some kind of final accounting to God. In a way, it's a kind of parallel revenge to the one that's been taken on his father.

This sense that death was something that you needed to prepare for, that it was something that could be done with an art, is one that appears in religious literature throughout the sixteenth and seventeenth centuries, whether Protestant or Catholic. In some sense, the difference between the human and the animal, for example, is the way in which humans can make an art of dying, whereas animals merely expire. Animals don't have souls, they can't deliberate. Unlike humans, they do not have to atone for life, make some accounting for it, and prepare for

death. That art of dying is one that is underwritten by a variety of theological prescriptions. And one of the things I noticed in this morning's panel was the way in which our discussion takes place in a very different cultural moment. The continuity between this life and the next one is not necessarily assumed, and this in turn changes our sense of how one prepares for death, what kind of action should be taken, what practices are necessary.

Another moment in the play, another ending that seems to be subject to very careful manipulation, is the elegy that Gertrude gives for Ophelia. The elegy is, in a way, an attempt to cover over both the history of Ophelia in the play and the specific circumstances of her death:

Here as a willow grows a slant a brook,  
That shows his hoar leaves in the glassy stream;  
There with fantastic garlands did she come  
Of crowsfeet, nettles, daisies, and long purples,  
That liberal shepherds give a grosser name,  
But our cold maids do dead men's fingers call them.  
There on the pendant bows her coronet weeds  
Clambering to hang, an envious sliver broke;  
When down her weedy trophies and herself  
Fell in the weeping brook. Her clothes spread wide  
And, mermaid-like, awhile they bore her up:  
Which time she chanted snatches of old tunes;  
As one incapable of her own distress,  
Or like a creature native and indu'd  
Unto that element: but long it could not be  
Till that her garments, heavy with their drink,  
Pull'd the poor wretch from her melodious lay  
To muddy death.

The event which places Ophelia in the water is the breaking of an envious sliver. Her own agency in her death has been erased, and the elegy seems to tilt the entire scene, so that gravity itself is conspiring with her to send her into this naturalized ending. It is a gradual death. We don't have any access to the secret

behind it, but we can infer it. But again, I think, language and poetry are being used to provide a shield. We were talking this morning about the ways in which art might either make the experience of death manifest or it might hide it. And I think here it's clearly doing the hiding.

Early modern spectators of *Hamlet* would have paid careful attention to these moments, since in the ending of any life could be found the reflection of life as a whole. Mortal endings were best when they were scripted deliberately, when one prepared for death as if one were going to welcome it as a gift. Certainly, you shouldn't discover it like some kind of serpent in a garden, something that sneaks up on you. I think that's really the heart of anxiety.

While death was clearly a journey into something else, the unknown country which Hamlet refers to in his soliloquy, the preeminent early modern anxiety about it concerned suddenness. However, when it speaks, like the voice issuing out of the black box, it can reserve some of its terrible finality for the living. This is the voice which speaks to Hamlet when he meets the ghost in the parapet, the voice of a father who died suddenly "with his sins on his head, his belly full of bread."

This is the voice which speaks to us as well. *Hamlet*, the play, is like one of those black boxes. In it one can hear the echoes of something that has been captured from oblivion and brought back to life. We may not share its audience's anxieties about having time to unburden ourselves in anticipation of a final accounting. But it's clear from our fascination with situations like the ones recorded in the cockpit that the suddenness of death has retained its full measure of power.

All this became clear to me several months ago while I was teaching the play *Hamlet* to some undergraduates. A few weeks before I had been involved in a serious car accident in which my compact car struck a cargo van on the Interstate. I had been teaching in order to give myself something to do while I was recovering. I had a broken ankle and broken hand, and could move myself around with something that looked a little bit like a glorified skateboard. I would get in front of the class and we would do readings of the play. We were reading the scene in which Polonius meets Hamlet and tries to draw the prince into his confidence. Hamlet is being evasive. He points to a cloud and says, "Doesn't this look like a camel?" Polonius agrees. "How about a weasel?" Polonius agrees. Suddenly,

Hamlet switches, “Or like a whale?” These words, I realized, described exactly what went through my mind as I looked ahead on the highway and saw the white cargo van fishtailing across the passing lane into my own, weeks earlier. As one of my students read the line aloud to the class, I could not help but feel uneasy. It was the first time that I had remembered what I had been thinking before the crash.

Hearing those words again while I was supposed to be directing a discussion made me feel helpless, disoriented and angry. Later, in my office, I tried to replay the scene in my mind, those weird moments of delay before the impact. The image of the van in the rain seemed almost playful, unreal, not very far from Hamlet’s description, actually. But the memory led to an odd question, and this was the question that really made me realize what had happened. What if this had been the last thought of my life? Couldn’t memory have supplied a better image in this last split second than a minor remark from a play so full of exalted poetry? Why not the face or voice of someone that I love? Why not some feeling of summing up, or just plain terror? I felt cheated.

When I saw the images this morning, Jim’s photographs, I thought about the way in which he had become a spectator at the death of his father. And that was the feeling I had as I was waiting to hit the van. I don’t remember the impact. I remember the sound of the impact. And I remember being pulled out of my car on a spinal board, and put into an ambulance and taken to an emergency room.

What’s traumatic about that experience, I think, is that I wanted to put a certain value on that moment and I couldn’t. There was a specific way in which the story of my life should end, and that wasn’t it—thinking about a whale.

I want to reflect on a few things, and then I’ll end. I think there is a lot of continuity between our own fascination with the moment before death, our attempt to prolong it, to enhance it, to stage it, or to cut it short, and the sense of death as interruption in the early modern period. We too have the desire to retrieve something from that moment, and to place it in a narrative. We have technologies to pull meaning out of these moments. Photography is one of them, poetry is another, and so is memory. And, in effect, many of these different devices help us approach that experience and tell a story in which that particular moment will be rendered meaningful. And being able to tell that story so that it leads naturally into that moment is very important to us, and it is certainly important to the spectators of *Hamlet*.

Here are two thoughts. First, what is the difference between recording, as done by the flight data recorder, and understanding? There's a way in which the flight data recorder can tell us what was said in that last moment, but it can't tell us how to tell the story of the lives of those people who died or who survived. That particular job isn't done by an individual; it's done by an entire culture. And in order to tell that story, we have to draw on the resources that our culture gives us.

The second: What's the difference between privacy and a crowd in this last moment? If death entombs a secret, is it a secret that has to be told to someone else? We talked this morning about the woman who says, "If I have to tell that story, it will hurt me." Why is it that death holds a secret, and who is the proper audience for that memory?

**Lawrence Schneiderman, M.D.**  
**Bioethicist, University of California, San Diego**

Earlier in my career—and I’m no longer a primary care internist, I do ethics consultations exclusively—I used to make a point of visiting where my patients lived, so I would get a sense of what their life was like. And that meant I occasionally would have to go to nursing homes. What was striking about these assisted living and nursing homes, I’m sure you see it, is how timeless they are. They make sure that there are always low maintenance shrubs, that the swimming pool is full of chlorine so it’s perfect, that the building is clean, impeccable. There is no sense of cycles or seasons. The ideal is to be clean and permanent, hygienic and concrete. There is no mud.

Because we only have a brief period of time, I’m going to speak to two topics, which I think help us look at this matter of time. The first is the type of persistent vegetative state, which also moves to permanent vegetative state; the other, to which I will turn briefly, is dying with and without modern technology.

Now, just a brief lesson in neurology. You have in your brain the cerebral cortex, which is actually a very thin structure on the outer surface of your cerebral hemispheres. Four to six minutes of anoxia, lack of oxygen, destroys that completely. The rest of your brain, particularly the brain stem, can survive for fifteen or twenty minutes without oxygen. That disparity accounts for what we now see in as many as 30,000 to 40,000 people being kept alive in permanent unconsciousness. Usually the cause is failed CPR, or occasionally a stroke or a motor vehicle accident of some sort. What happens is that that part of the brain,

the cerebral cortex, which is us, our personality, who we are, how we think—our capacity to experience, see, hear, think, emote—that may be permanently destroyed. Whereas the rest of us, the brain stem, which gives us the ability to breath, digest, all the organ functions, that could be kept alive, and in many cases has been kept going for decades. And so that has given us this condition which was first diagnosed in 1972. It's really interesting, that that's a very new disease as far as medicine is concerned, and, in fact, it's an iatrogenic [doctor-created] disease. Vegetative state is the condition, as we call it, but persistent or permanent is what we do to keep that condition going. So in a sense, that's a very important notion.

Now, all of us who do ethics consultations, have had the experience, and I've had several, where families have insisted that their loved one be kept alive in a permanent vegetative state, permanently unconscious. And this is a clinical diagnosis. If someone, for example, has persistent vegetative state, where their eyes may open and close and they have all sorts of reflex capacities, that's because that part of the brain stem, the reticular activating system that's responsible for sleep/wake may be temporarily impaired, but then recover. And so they're unconscious. Their eyes may open, and they sleep, but they're completely unaware. Families will sometimes demand that physicians keep such patients alive—and it's very simple, a feeding tube and good nursing care will do it. There's nothing more that has to be done, if that's the condition we're talking about.

Now, I've either been involved in or heard of cases where families have demanded that this be done, and the patient has been kept alive for eighteen months although there is no realistic chance that the patient will ever recover. I have to admit that today, hearing about embalming made me think of the parallel, that this was a family that needed to see that person in an embalmed state. It's truly nothing less than that, if you consider the person, the capacity of the person to interact.

I've also heard this described as a tragedy: "Oh," one says, "the person who had this happen to him, it's a tragedy." And I have to say that I'm with Martha Nussbaum on this, that this is not a tragedy: this is hubris, this is a failure to recognize our mortal limits. I refer here to a very rich and perceptive essay, "Transcending Humanity," where Nussbaum talks about Odysseus, whom Calypso was trying to tempt to stay with her. Calypso says, "You stay with me and

you will have immortality and ageless love.” What could be better? But Odysseus, even knowing that his waiting wife Penelope is far beneath the beautiful goddess in form and stature—and I’m quoting Nussbaum:

opts to continue his voyage, thus choosing not only risk and difficulty, but the certainty of death. And not only death, but the virtual certainty that he will at some time lose what he most deeply loves, or will cause by his own death great grief to her. He is choosing the whole human package, mortal life, dangerous voyage, imperfect mortal aging woman. He is choosing quite simply what is his, his own history.

What I think we call a tragedy is closer to farce. That sounds very brutal, but I think we fail to recognize that tragedy requires us to understand that death comes, death is what ends us because we are mortal. And our unwillingness to accept this comes close to the comic notion of doing too much or seeking to go beyond our powers and hence making fools of ourselves. This is, in fact, the definition of comedy. I think that permanent vegetative state really exemplifies the failure to understand our mortality.

Now, in ethical terms, there is also the argument that keeping patients alive in this condition may be harmful, but the argument is usually made by those who say, “If that’s what people want, if that’s their values, we should honor it.” And after all, if someone is permanently unconscious, they’re not suffering, so you can’t say we’re doing harm. How do you know, anyway? What do we know about the patient who is permanently unconscious? Only that he or she is isolated from any form of communication, as though exiled or banished from society, a condition once regarded as punishment equal to if not worse than death because it is, in effect, dehumanizing. From the earliest known time, human beings have functioned as organic components within a community connected to family, friends, work, rituals, customs, duties and entertainments. In early Christian society, banishment served, along with burning at the stake, as punishment for heresy, thus apparently being deemed equal to the most painful death.

Finally, I want to make a few specific points about dying with or without modern technology. First of all, some of you, I’m sure, are aware that today about

80% of people die in a health care setting of some sort, only about 20% die at home. So those of us who are in health care have a lot to say about how people die, and if we pursue certain measures, they're going to die one way. If we at some point recognize the importance of palliative care, comfort care, they'll die another way.

There has been a great debate about whether to withdraw artificial nutrition and hydration. And I still run into physicians and families who say, "Oh, we can't let them starve to death. Oh, we can't let them die of thirst." Fortunately, we've had Hospice, which has pointed out that terminally ill patients, patients who stop eating and no longer seem to want to drink except perhaps sips of water, die more comfortably than patients on whom we force artificial nutrition and hydration—we increase respiratory secretion, we increase the risk of nausea, vomiting, aspiration, pneumonia; we increase the amount of incontinent urine that they produce. So, in a sense, we influence the time of dying just by one simple measure of not force feeding.

Now, this actually has important metabolic consequences, as it turns out. If you allow patients to die without being given glucose or other sources of carbohydrates, they then begin to use their protein and fat as energy sources. This creates ketones, a chemical in the body that seems to have an analgesic effect. More than that, metabolic acidosis seems to have a euphoric effect. A professor of English, a friend of mine, called me one day, and said that her mother was dying of cancer in a nursing home, and there was a big fight in the family about whether or not to put a feeding tube in her in her last week so that she would live longer. In talking with my friend, I strongly urged against putting in what we call a peg tube, a subcutaneous feeding tube. About a month or so later, she called me and said she was so grateful. Her mother died, she said, an ecstatic death. She had this wonderful kind of peaceful, serene vision that accompanied her dying days. And it occurred to me that that's what we have been depriving modern patients of, that possibility, by insisting on replenishing their food and fluids.

What about withdrawing a ventilator? Some of you may say, "Well, if a patient is ventilator-dependent, in other words, requires artificial respiratory health, what do we do, do we keep that person on it?" Well, today, if it's no longer beneficial to the patient, or if the patient refuses it, it's good medical practice to withdraw it with plenty of morphine to make sure that the patient is comfortable. This is not euthanasia. It simply makes the death shorter and more tolerable.

Another treatment that I see which very often confuses effect with benefit—I'm very conscious of the fact that we can do so many different things, which we call effects in medicine, and sometimes we fail to recognize those effects that don't have a benefit—is giving drugs to raise blood pressure. When patients die, their blood pressure goes down. How many times have I seen doctors starting to infuse what we call vasopressors to keep the blood pressure up while the patient dies. If the patient is unconscious it serves no purpose. The only reason to do this in the terminally ill patient is if raising the blood pressure means that the patient then becomes conscious because of blood supply to the brain, and can enjoy the last few days of life or moments of life. Too many times I've seen the procedure done, prolonging the dying process, with no benefit to the patient. So there, too, we do manipulate time.

One other point. When we decide that the patient will no longer survive, we should get rid of all the impediments to looking at this person whole and intact. So take her off the monitors, take her off the IV's. Create the situation where the family will not be looking up at the cardiac monitor, rather than looking at mom. If the mother wouldn't have wanted to go with all the monitors, that should not be the image that this family should take away.

In conclusion, there's a wonderful passage from Willa Cather's *Death Comes for the Archbishop*, which I just would like to read to you. And keep in mind Michael Witmore's comments about the black box because that, too, struck me as a very interesting parallel. In the book, Cather writes,

In those days, even in European countries, death had a solemn social importance. It was not regarded as a moment when certain bodily organs ceased to function, but as a dramatic climatic climax, a moment when the soul made its entrance into the next world, passing in full consciousness through a lowly door to an unimaginable scene. Among the watchers there is always the hope that the dying man might reveal something of what he alone could see, that his countenance if not his lips would speak, and on his features would fall some light or shadow from beyond. The last words of great men, Napoleon, Lord Byron, were still printed in gift books, and the dying murmurs of every

common man and woman were listened for and treasured by their neighbors and kinsfolk. These sayings no matter how unimportant were given oracular significance and pondered by those who must one day go to the same road.

It's clear how differently we feel about this. Today, death is regarded as the enemy. We are mostly considered as dying in isolation. Those who were hoping for miracles also feel death as a betrayal. To die is perceived not as something inevitable, a moment to be treasured, but as an avoidable mishap. "If only the person had the strength of character to hang on a little longer, until the inevitable miracle drug came along." Death in this secular age is rarely promoted as an opportunity, rather than as a defeat.

# Comment

**Guy Micco, M.D.**

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Dr. Tripathy talked about new technological advances in the treatment for cancer, and pointed out that they are small, really small, and that promising things are on the horizon. That is the same thing that I think he heard fifteen years ago when he went into practice, and the same thing I heard twenty years ago when I went into practice: things are on the horizon. Although Dr. Tripathy didn't label it as such, the problem of "informed consent" is bound up in all of this: how do we best help the patients who are vulnerable because they are sick make a decision to accept or reject a new treatment which may or may not be beneficial to them? Dr. Tripathy said that the process of educating patients to be able to make an informed consent is incredibly difficult. And it's particularly difficult in conveying this uncertainty that's inherent in what we're doing, or what we're asking the patients to take on in a treatment, in particular, in this case, the treatment for cancer. This, at a conference we had a couple of weeks ago, some of us called "the first error of physicians," not conveying that uncertainty to patients. I was happy to hear Dr. Tripathy say that that's one of the first things that is necessary to convey to patients. The statistics may show one thing, but the fact of what will happen in any one particular patient is unclear.

Why do physicians not convey this uncertainty? Either out of ignorance, or more likely, I think, out of an attempt to protect people from a potentially grim prognosis. We're very bad at talking about prognosis with patients. That was the

subject of a study that came out recently, that some of you may have read about in the papers: physicians and oncologists don't tell the truth about what they feel is their best guess about prognosis, and they may not tell the truth to themselves. And the truth is that it's a best guess. But further, their best guess is often not conveyed to patients.

Michael Witmore spoke about death in the early modern era and the fear of suddenness. I think of the prayer, "Oh, Lord, give me a conscious death." If that was the feeling of the public, well, it apparently has changed. It has been said that all Americans fall into one of two camps: either wanting to die consciously or wanting to go quickly. I suspect most people here would want to say that they would want to go consciously, but, think again, please, because it's not quite so clear as it sounds. If, in fact, this is the dichotomy, most commentators say that Americans want to go with their boots on or, alternatively, asleep. It appears that unconscious wins. A conscious death is not necessarily something devoutly to be wished for in our culture today.

Let me move to Dr. Schneiderman and particularly to his remarks on persistent vegetative state. Larry and I have had discussions about this before—we both agree and we sort of disagree. But as he knows and you all know, the value of life for probably most of us in this room is the value that we place on our personhood. We, not surprisingly, find it completely foolish to continue a life that's devoid of those characteristics that we find most valuable and important to us. That is, we don't place as much value on the mere fact of life. As Dr. Schneiderman noted, however, and as I'm sure you know, others have a different sense about it. The mere fact of human life is immensely valuable to them, even perhaps when faced with a loved one who is in what has been aptly but terribly called a vegetative state. I have no answer to this difference in perspective but it needs to be acknowledged.

Let me turn now to some remarks of my own. I'm going to start with an anecdote. This is the traditional pedagogical method of my profession—it used to be the preferred method; and although it's come into problem times, still, I think it's a good method to use. The anecdote is that of Mr. Reggie—clearly, not his real name. Mr. Reggie died in our local community hospital not too long ago. He died one of the ever-more-common planned deaths in the Intensive Care Unit. Planned deaths have been reported to be as high as 90% of Intensive Care Unit deaths.

Two nights before his death he had had a stroke. It was a big one, with bleeding into his brain, and he became comatose immediately. He was 85 years old. That we know of, he had no pain, no anxiety, no need for symptom control. But just as the paramedics got him to the hospital, he had a respiratory arrest, he stopped breathing and required mechanical ventilation. When I saw him, he was in the ICU, the Intensive Care Unit, in a coma, on a ventilator, with his family around the bedside. We all agreed that he would not want to continue like this if there were not a reasonable chance for some recovery. After reviewing his brain CAT scan with a radiologist and a neurologist, it became apparent, quite clear, actually, that he didn't have such a chance. So Mr. Reggie's family and I decided that we would all meet at his bedside the next morning and turn off the ventilator, "pull the plug," in common parlance. We planned his death.

The next morning, Mr. Reggie's wife and children and minister met me as planned at the bedside. I explained that I was going to turn off the ventilator, pull out the so-called endotracheal tube that had been inserted into his throat, the equipment that was delivering air or oxygen to his lungs. Since I believed that he would not be able to breathe on his own, I said that this would result in his death. I proceeded to do as I described and, indeed, Mr. Reggie never took a breath on his own. He was dead by one very old criterion.

But something unusual then happened at his bedside. Mr. Reggie's heart's EKG, electrocardiogram monitor, was on, just above and to the left of his head. And we all stood there transfixed by this electronic representation of his life, watching the ever-slowng tracing of the electrical activity of this man's dying, or what we thought was this man's dying, but not yet dead heart, and listening to its soft beeping accompaniment. Mr. Reggie was in some strange liminal state, as were we, for what felt like a very long time.

Then somehow—I have no idea how—perhaps it was my discomfort with what was happening, or perhaps it was a glance from his wife, something broke the spell, and I turned off the monitor, announcing at that time, as doctors are want to do, that the patient had died. The family then turned their gaze and attention to their beloved husband and father, and the minister said a blessing.

But was Mr. Reggie really dead when I pronounced him so? The timing of death is important to us for a variety of good reasons. We want to be sure when

someone has died. In the Intensive Care Unit, we want to be very sure that someone has died. It's not a place for these kinds of errors. "Dead?" "No, no."

Some might think, and some have told me, that this patient wouldn't have died until his monitor showed no electrical activity of his heart, that I shouldn't have turned off the monitor, or I should have kept watching the monitor myself at the nurse's station, and pronounced him dead when the electrical activity went to so-called "flat line." But virtually anywhere outside the Intensive Care Unit, unless the person is hooked up to an EKG, an electrocardiogram, at the end of their life, death is determined as it has been for, again, a very long time. You are dead when, first, you look dead—no movement and some other qualities, like, for instance, big pupils that don't budge when you shine a light on them. One of my colleagues, a seasoned oncologist, claims to know when someone dies, absolutely sure she says, when they have a waxen look to them. This happens "within a minute," she says. Within a minute of what is unclear. One might be concerned with the validity of this looking-dead criterion; it has a high sensitivity; there are no false negatives: when you're dead you always look dead. But its specificity is something short of 100%: not everyone who looks dead is dead.

So the second traditional criterion of death is that you stop breathing for much longer than you can reasonably be expected to hold your breath. This is actually my preferred criterion. I'm with King Lear on this one. He stands over Cordelia: "I know when one is dead and when one lives," he says. "She's dead as earth. Lend me a looking-glass, if that her breath will mist or stain, why then she lives." Or for a more up-to-date example, take a recent Stephen King movie (I was in the video store, finding something very highbrow, I assure you, to watch, and this was going on in the background). Two children are traipsing through a forest and come upon a third child, a non-moving child, one of the duo says, "He looks dead." And the other responds, "He's not dead, stupid. He's still breathing." It's part of our human understanding, I think, to equate breath with life. It is in our languages, the word for breath often being the same word as for spirit or life force. In fact, the first definition of "spirit" in *Webster's Second* is "the breath of life, life or the life principle." Or take *Genesis*, Chapter Two, Verse Seven, "Then the Lord God formed a man, Adam, from the dust of the ground 'Adama,' and breathed into his nostrils the breath of life." Thus, to extrapolate, you die when you expire, when you breathe out your last breath.

You might consider now with me the power of the mechanical ventilator and what that has done in the last thirty years or so.

The third traditional way to determine death is when the heart stops beating. And this is actually pretty unreliable—it certainly was, for sure, before the invention of the stethoscope in the early nineteenth century. A weak pulse, one sufficient for life can be very difficult to feel. And even with a stethoscope, some hearts beat faintly within and can be missed. Having done so, I can attest to this. Thus, the usefulness of the heart monitor, the electrocardiogram or EKG, which shows the electrical activity of the live heart. I'm not against EKGs, but I don't want to give too much over to them. In particular, I want to note that a heart's electrical activity is not sufficient for life, nor is its absence a guarantor of death. Specifically—I'm hoping here not to be too technical—the heart may have electrical activity as shown by a cardiogram or heart monitor that does not lead to the mechanical activity, the pumping of the heart, sufficient to sustain life. And the absence of this electrical activity is insufficient to call death because this activity may be restored within a few minutes. And death is irreversible, isn't it?

I will also take a cheap shot at the technology, by saying that it is liable to error. A so-called lead falling off, and a very live patient can look very dead on a cardiac monitor. The EKG is, thus, not a very sophisticated bit of technology, and though it's quite useful at times, it's a poor test and an unnecessary test for determining when someone has died.

So I've given some ways to determine if, and perhaps when, someone has died. I've evaded the simple yet embarrassingly difficult question: What exactly is death? I seem at once both to know and not know what it is. *Webster's Second* says death is “the cessation of all vital functions without capability of resuscitation.” But this, again, really speaks to the question of *when* death occurs: when all vital functions cease, without chance of resuscitation. So I'm going to take the chance and revive, again, a very old definition: Death is the absence of a life force. It occurs when the life force leaves the body. I don't know what the life force is, but I do know that breath and breathing are intimately associated with it. Thus, death occurs when we expire our last breath.

Now back, quickly, to my patient. At the end of his life, Mr. Reggie had a machine breathing for him, literally keeping him alive. When this machine was

stopped, we watched as his last breath was breathed for him. As we observed his heart monitor, several minutes passed; he was not going to breathe again. His life force had left him; he had expired. The heart monitor, showing the heart's electrical activity, had really nothing to offer us, but we were for awhile so taken by this electronic technology that we tended more to it than to the real thing, the patient in the bed before us.

**Session Two:**  
**Time—Counting the Moments/Making Moments Count**  
**Discussion**

GAIL GREEN, PANEL CHAIR: I think I'm going to turn to the panel, and ask whether any of them has a response to anything that has been said.

MICHAEL WITMORE: Well, I wanted to say a little bit about the historical context of anxieties, about suddenness and death. I think I probably short-changed that topic. Memory is not a black box. And at least with Calvin's *Institute*, which was published in many editions in England, in the late sixteenth century and through the seventeenth century, we get a lot of arguments about what one should do when one sees an accident or a sudden death. And the usual recommendation is to regard and wonder at the event. And this is taken up in English popular print literature, which chronicles accidents both in England and in Europe and Ireland, and is always urging the virtual spectator who reads that pamphlet to look at the incident and then expect in some way that it might happen to you. I found probably between seventy and one hundred of these pamphlets or short books published between 15 A.D. and 1630.

One of the ways in which this desired posture is described, and I think it's the posture of readiness, is as a kind of split vision. So William Perkins, a Puritan theologian who publishes a long book in 1600 called *The Golden Chain*, describes how you should with one eye fix on the disaster, and then with the other eye, your spiritual eye, focus on God. It's this odd kind of divergence of vision which, if cultivated, will prepare you for what can't be anticipated.

But I think, certainly, it's not just a theological position, it's a practice, and it's one that's encouraged by popular print and narratives of the kinds of

disasters that are happening all the time in London. For example, where there's no fire department there are a number of fires, plague is breaking out all the time, etc. In short, there is a very visible confrontation with death.

GAIL GREEN: Yes, that divergence of vision I thought was terribly interesting. It's something that is also implied when you take a photograph of a dying person or when you start to write about a dying person. You find yourself, as I have found myself, there and not there—kind of there participating to a great extent, and drawing back and observing, and trying to make it into something artistic or meaningful. And when you described your accident you had somewhat that same response that you were talking about, somewhat divided as you observed what were almost your own last moments. But then it wasn't your death, so you don't really know.

LAWRENCE SCHNEIDERMAN: I want to respond to Dr. Tripathy with a quick point about time. I talked about time in some ways, but he mentioned a very important one, the time spent between the doctor and patient. I am very concerned about the erosion of that time, and I have some specific empirical data, which I'm sure is going to offend someone here.

About twenty years ago, we did an interview of patients in the Bay Area who were seeing homeopathic practitioners. Now, I think homeopathy is quackery, it's sheer quackery. But we interviewed a hundred patients. These were people who knew about science, were very highly educated and sophisticated. They had chronic illness that was incurable by our technology. What they got from the homeopathic physician was something very interesting. Each patient would be asked at great length and in great detail, her or his specific symptomatology; each was individuated over a long period of time. And there was a great deal of time devoted to this process.

What we do in contemporary Western medicine is take each person with a set of symptoms and lump them together into a category—"Oh, you're heart disease, you're lung disease, you're kidney disease." And so we de-individuate them. And then that's compounded by the fact that now, with managed care, we are forcing physicians to do this in less and less time, in order to get the output going.

DEBU TRIPATHY: Apart from time, which is clearly a critical factor, we lack a role model. We all lack role models in how to die, or most of us do. It's not something that we are acculturated to. It's a very foreign thing. And it's foreign to physicians as well. Physicians-in-training do not get the kind of mentoring and role modeling that they once got. Their ideal role model is someone who can recite biochemical pathways and knows pharmacology and molecular biology and can make an astute diagnosis. However, for those of us who treat people with cancer or any chronic illness, the diagnosis is the beginning, not the end. And so it's everything that comes after that that is important. Some of the medical school curricula now are paying some attention to role-playing and role-modeling, although I don't know if they can find instructors who know how to do that at this point. But in addition to time, I think there's a way to know how to do it.

And, you know, there's an incredible fragmentation in medical care too. You don't only have your doctor, you now have the advice nurse, and you've got the case manager and the social worker, and you've got a lot of other people who are trying to work in a team. But, clearly, they have their own opinions and sometimes they can actually give you mixed messages.

So it really does fall on the physician, I think, still, even in this modern era, to be the primary person to provide the solace, as well as the advice, as well as the medical care. And I don't know what the future of this is going to be. You know, being at a university practice, I've been able to hold onto my half-hour appointments for follow-up and one hour for new patients. But that's very unusual in the field; most people have half that amount of time. And I'm concerned about that. That's one area of medicine where I don't have an answer as to where we are going. I'm very optimistic about technology and other movements in medicine—advocacy and all that—but I don't have an answer for the time factor. It's a precious commodity for everybody; not just physicians, but everybody has less time.

GAIL GREEN: I'm going to throw this discussion open to the audience.

ERNEST LANDAUER: Ernest Landauer [Bay Area Funeral Society]. A practical suggestion. The focus is still on the profession, but how do people learn to be patients? There are still many people at subsistence level or below, to whom

the whole practice of medicine is out of bounds because they can't afford it. So one of the undertakings that seems to be very important is that in primary and secondary education there be included in health studies how you take on various roles, including the one of being sick, of being a patient, in a highly technologically ramified society and a highly monetized society.

DEBU TRIPATHY: That's a very interesting point. There is an emerging field called collaborative care, where we try to teach our patients how to use resources and time wisely, and how to choose the questions that they might ask. So it's a very new project that we've started to undertake. But, I must say, the patient that comes armed with questions and an agenda strikes fear in the heart of many physicians because they see this as a big time-sink; they see this as requiring extra explanation and even research. It carries a negative overtone in the medical community. It shouldn't. I think that the inquisitive patient might take some more time initially, but I think in the long run, the well-informed, satisfied, well-read patient is going to take less of your time and enter into a more satisfying relationship with the physician.

Many times when patients come to see me with breast cancer, they do take a very long time, especially if they've read a lot and read things on the Internet. It does take me more time. But what I spend my time doing is teaching them how to be good researchers of information. I give them some guidelines on what is good information, what is bad information, what is trustworthy, what isn't, what they should look at in clinical anecdotes versus clinical trials, and how they should apply that information to themselves. And over time, I actually find that our subsequent visits take less time because they are actually doing a lot of the work themselves.

TONY BECK: I'm Tony Beck, University of Washington. I wanted to ask the panel to reflect on the question from this morning about what people need when they're dying, especially since you've all talked about technology in different ways. It strikes me that maybe technology distorts the whole issue a little bit, and I'm wondering if that has to be so. I'm an oncologist also, and I see that patients, if you ask them what they need when they're dying, would say, "I need more options." And one of their options needs to be "Maybe I'm not dying." I'm

thinking about the Bristol Myers Squibb commercial for chemotherapy I saw on CNN. It shows Lance Armstrong winning the Tour de France. Patients see that he thought he was dying, and actually, he turned out fine. He won the Tour de France.

LAWRENCE SCHNEIDERMAN: One phrase that I try to have students interpret in a meaningful way is, “Do everything.” Dr. Tripathy mentioned that patients say, “Do everything.” The family says, “Do everything.” And immediately we tend to interpret this as CPR, ventilator, dialysis, and all those technologies. When, in fact, at some point, it’s comfort care, and it’s definitely not CPR, it’s definitely not a ventilator. So “do everything” really has to be interpreted more broadly as “do everything that will benefit the patient.”

DEBU TRIPATHY: I think it’s important at the very beginning to lay out what the expectations might be. The way I initiate this with patients is to give them a spectrum of what we might expect from their situation, whether it involves new technology or new experimental therapies. And once you frame that, it becomes a lot easier to go back and allude to it. You might say, “Look, the worst case scenario is your cancer may be very resistant to everything we do, and things may deteriorate quickly. The best case scenario is that you have a great response to this treatment, and you have a great quality of life, and a very long remission. And, you know, my job is to guide you through this and try to give you the best advice that’s going to get you on the best end of the spectrum. However, if we are on the bad end of the spectrum, we are going to turn our attention, turn our focus, to the kinds of things that will make a difference given the situation we’re in.”

I find that once we look at those boundaries, and I talk about the best and the worst, that not only have I given myself some space to walk into later on in the worst case scenario, but I’ve given them the hope of the best case scenario without misleading them because I’ve given the whole range. And, in fact, most human diseases, most chronic diseases, fall into a very large spectrum.

JUDY MARTIN: I’m Judy Martin, a physician as well. And I was thinking this morning and also this afternoon about the body. We’re talking about autonomy and decisions that are sometimes in opposition to what the body is actually

doing. I'm thinking of the pictures this morning, the pictures from the nursing home. Who exactly is this "I" that's saying, "I live too long," when the body is continuing to live? So I would like to hear some comments about communicating with the body, working with the body, or looking at the body's role in autonomy and decisions. Obviously, in many cases, the body has "decided" to continue living

LAWRENCE SCHNEIDERMAN: Guy and I often come to some sort of conflict over what to do when you have a body without a mind. And I now think that we are going to have to compromise, to say that there is always going to be Guy's position and there's always going to be my position, and there's no way to resolve it. So let's be friends and say some hospitals will have policies that say, "We don't keep people alive who just have bodies and no minds and are permanently unconscious," and other hospitals who will say, "Well, we do." And so, in a sense, the mind-body problem, so to speak, is going to be resolved the way good old Americans do it, by compromise.

I don't know if that helps, but I do think that medicine is constantly examining this relationship between what we call our personhood, our capacity to interact, which philosophers say is the basis for moral decision-making, and the fact that we all lug around this flesh and bones that we can't escape—we can't be a person without that stuff.

GAIL GREEN: I just want to quote Yeats, "My soul fastened to this dying animal."

FRANK GONZALEZ-CRUSSI: I think that the medical profession is also responsible for the high and unwarranted expectations of the public. It's not just the media. The example that I often give to substantiate this claim is that the choice of terms favored by the medical profession is sometimes exaggerated. I think of the case of CPR, cardiopulmonary "resuscitation." They could have been more modest, they could have said something like "physiologic reactivation," but they were not happy with that. They wanted "resuscitation." It's bringing back the dead from the grave. It's not the physiological feat, it's the biblical feat of Lazarus.

My other comment is prompted by Professor Witmore who mentioned that recordings are artifacts of our own creation and they merely reflect our interest in death. I would say that everything that is stated about death is purely an artifact of our own creation. In other words, we not only do not know anything about death in an essential sense but cannot know anything. It is something we cannot know because it is outside of the realm of general experience, or if you want to put it in technical philosophical terms, it's not empathic but meta-empathic.

Dr. Tripathy was talking about how we have no role models. I mean, how can we talk about learning how to die or the “art of dying”—I think that was an expression that was used today—when there are no role models, there are no teachers, there are no professors. Again, what do you mean by the “art of dying,” that you should develop some patience and some fortitude? Well, that's generally, you know, proven in life, but it is not specifically about the art of dying.

We heard Professor Micco talking about death as the cessation of electrical activity. Well, that's purely a practical experience. So we know that lawyers are not going to sue us for stopping supportive life measures. Is it the decision of other physiological parameters? There was a time, you know, when I was young and foolish—now I am no longer young—in which I really wanted to have an accurate and comprehensive definition. It's not a cessation of electrical activity, it's not the cessation of other physiological parameters, because even after a patient is dead you can take pieces of the aorta or grafts of the skin and they continue on living. So that's not the complete cessation of all physiological activity. It can be framed in mathematical terms, by current definitions of mathematical terms, but they are insufficient because they don't account for our own death. And, lastly, the life force that Dr. Micco also mentioned is too vague because it does not refer to our own individual deaths, which, after all, are the ones that count.

MICHAEL WITMORE: At the risk of advancing the philosophical pursuit of the useless, I'm uncomfortable with the idea that because the experience of death is one that we have to interpret, one that is open to cultural influences, that it is on those grounds unknowable. We don't have to commit to an artifact/culture versus the body/nature model, but rather there might be some form of collabora-

tion. I don't know how I would flesh that out. But it's that sense that it's utterly unknowable because it involves interpretation that seems foreign to me. It may be knowable precisely because it's cultural. And that's nothing to be optimistic about.

FRANK GONZALEZ CRUSSI: That's what I mean; I'm going for certainty.

TOM COLE: I'm Tom Cole from the Institute for Medical Humanities. When I was listening to Guy's talk, I was remembering Jim's line this morning, "I could feel the difference, but I couldn't see it." So much of that wonderful series of photographs was an attempt to see it, help us see it. And I'm left still wondering when the hand says 7:41 in the foreground and in the background is the father. Is he dead? Just because that picture says 7:41 and we're supposed to think he's dead, do we know? So I don't think the uncertainty is removed about the issue of timing of death, the nature of death. The reason that Philippe Arias needed to help us see past historical eras and past artistic representations is that death is no thing; it loves to be represented, it has to be represented, and sometimes personified. Is it an archer? Is it a grim reaper? Is it a kindly nurse who puts you to sleep after your day's work is done, after your night's work is done? We need these cultural representations, and I think they are very important to us. Are they true? I don't know if they're true or not.

And the life force, to me, is an interesting attempt to go backwards, you know, 100 years, to the point where in the history of science people rejected that idea, saying it's not quantifiable. Say there is something useful in this idea that, like Jim, "I could feel something but I couldn't see it." Is it the life force? How will I know it when I see it? I mean, I think there's something to be pondered and worked on in that.

In terms of the literature of death and dying, since we don't have exact tests for determining death, people should be able to negotiate. As Linda Emmanuel suggested, why not let patients decide in relationship to their caregivers, which definition definitely applies to them. And that way we'll know when you are really dead, or at least the person who survives them will. I think it's, in a way, interesting and, in a way, terribly evasive and impossible.

In preparation for death I learned a whole lot this summer from a twenty-three-year-old man in Salt Lake City, who had a terrible case of Ewing Sarcoma

and was a body donor. And so I interviewed him and video taped the interview for the film that I'll show you a little bit of tomorrow. The goal of my interviewing him was to get him to talk about his life and his illness, and to speak to medical students with the wisdom of facing his condition. I learned a lot from him: he was ready to die and he was ready to live. One eye was on God and one eye was on the ground. And when I said, "Talk to medical students who will be working on you. What would you say to them?" he responded, "Get your lives in order. Decide what you want to go to whom, and what really matters to you." This was a twenty-three-year-old man. I then asked him, "What about your prognosis and your future?" He planned to fight it right to the end. So preparation for death doesn't mean that we roll over and play dead before we need to die. It's a dichotomy that I think we often fall into.

When we were speaking about expecting the end of the narration to appear, or how do you know what your last thought is, or wanting to memorialize your last moment, it reminded me of a journal I was asked to comment on a couple of years ago by Claire Phillips, a social worker from Cleveland, who was dying of cancer. This was part of a Geratological Society meeting, and I kept turning the pages with a lot of anticipation, waiting to get to the end. Well, there was no end, it just stopped. And what I realized was that Ann Wyatt Brown, who put this panel together, had helped write the end of the story. Our comments on Claire's life and our relationship to her, befriending her and then mourning her loss, and her family's presence at the sessions, were part of the ending of the story. We don't finish our own stories.

GAIL GREEN: Her story is silence. I'm thinking of that scene in the *Seventh Seal*, where death comes for the character. He doesn't find death, but death finds him. "Now, will you tell me your secret?" he asks. And Death says, "I have no secret."

PATRICIA BENNER: Patricia Benner from UCSF School of Nursing. It occurs to me that in this day we keep crossing over between death as human passage and death as a medically mandatory physiological state. And it seems that we should try to open up the social spaces, look at death as the human passage, and figure out if we're using clinical language as a proxy for human passage. But the other term we haven't mentioned a lot is this notion of, "What is it to have a life?" And

perhaps because we have trouble figuring out what it is to have a life, or live, that we won't be so good at talking about death as a human passage.

LAVERA CRAWLEY: Yes, I'm LaVera Crawley from Stanford Center for Biomedical Ethics. This is not really a completed thought but it struck me that Dr. Witmore's notion of the black box is really is one of the jewels to come from this conference. In the notion of recording versus understanding, or interpretation, I am reminded of the Egypt Air crash, and how we struggled over how we were going to make meaning out of what was stated on the black box and how we, as part of American culture, seemed to want ownership of being able to interpret the meaning, but, quite understandably, the Egyptians resisted that. How could we really understand what was being stated there?

LAWRENCE SCHNEIDERMAN: Is death a "human passage"—I think that was Benner's term—versus some physiological event? That's the problem. And if you say it's a human passage, Robert Beach is a philosopher who says, "We should say cerebral death." So when a person loses his cerebral cortex, that's death. But the only problem is then you say, "Oh, so I put this guy in a box who's still breathing and put him underground? No, that isn't death." So in a sense, we haven't solved that problem, what the difference is between a human passage and physiological death. That's the paradox, I think.

MICHAEL WITMORE: I think one of the interesting things about this topic is that it is difficult to talk about precisely because it links physiological fact and empirical problems to interpretive ones that we're just philosophically not equipped to parse. We tend to want to split them up. So it's no wonder that it's so troubling. It's hard for me to think of discounting your empirical account of death for one that was more philosophical or personal or narrative. It's hard to pull them apart.

PARTICIPANT: I would like to ask Dr. Tripathy if he has any comment on the recent controversy about the use of bone marrow transplantation for breast cancer patients. In the beginning, this seemed to be a viable alternative therapy, and the feminist community, in particular, was very gung ho about getting insurance

authorization, and so on and so forth. And now there are studies saying that it isn't that effective, and that doctors and the feminist community made a mistake in pushing this so hard because they ignored certain medical evidence. I had a bone marrow transplant, though not breast cancer, at a time when it was considered an experimental therapy, and I had to fight my HMO for three years to get them to pay for it. And so whereas my sympathies are more with the position that if there's hope you should fund it, when do you make the ethical decision to say that this is a viable therapy versus a non-viable therapy, and really go to bat with the insurance companies over it?

DEBU TRIPATHY: Well, the whole bone marrow transplant story is an exposé of over-optimism with technology and the very human tendency of wanting to fight for what one thinks is right. Right now, it appears as though bone marrow transplantation is not that beneficial in breast cancer, but there was a lot of excitement around the new technology. And I think that a lot of the impetus to push for it was, in fact, from the advocacy movement, as well as from physicians. They each had their own reasons for wanting to push it. It was, I think, an example of trying to put one's professional advancement ahead of what the clinical data showed. And for women who were supporting it, it was an expression of, "Society isn't doing enough for us, they're neglecting us and this is one way we're going to fight." In fact, in some states, laws were passed that required insurance companies to pay for bone marrow transplantation.

This was an example of the dissemination of technology outstripping our ability to study it scientifically. In most areas of cancer, we are going to have to do controlled clinical trials to determine the benefit of any of our therapies because our therapies aren't that good; they might incrementally improve outcome in a defined group of people, but we won't know unless we do clinical trials. So you raise an important issue: we have to deal with the emotionalism, as well as the science, in how we move technology ahead

JOHN GILLIS: This is just a rumination, but it goes back to Tom Cole's point that death is not a thing, but it does seem to attract to itself more creative activity, particularly in the 1990s. I'm not saying that it doesn't deserve it, but the amount of creativity—artistic, scholarly, and even medical—around this seems to be worth

commenting on. And I wonder, this goes back to the point that was made here, about the burden that death and dying puts on patients, as well as doctors. And it's a cultural burden, as well as everything else. I'm thinking here, today, we've heard about the various things that the dying and those around them are supposed to produce—wisdom, vision, oracular statements, heroic behavior. These are things that are pretty rare now in modern life, generally. In other words, I think we have to look at the absence of opportunity of these things in other areas of life, in order to explain why they're clustering now around death. And I would add to this, and this goes back to the point that I think has just been discussed, death is a mystery, it's an unknown. It attracts to it one of the great human characteristics, which is curiosity. So it's not surprising then that, the more we heighten the notion of the unknown, the more we should then be prepared for society's obsession around these issues.

And just one throwaway observation about this strange thing that's happened now in our culture, where we can conduct wars without inflicting death on ourselves. This is extraordinary—to my knowledge, a step unprecedented in human history. So now we're in a situation where death is domesticated more than ever before.

PARTICIPANT: Two comments about time and also the human aspect of what we're talking about. I often do bereavement groups, and when people are sitting in a circle telling their story about the person who died, I often feel as if the person who died is in the room. In the film that Dr. Micco showed us, we saw the transition that the dying woman was making, whatever it was. We can't scientifically ever know it, but each of us, individually, I would say, knows it on some level. And those people who have died live on in our lives in some way, through our memories or through our love.

I want to come back to these two questions of the morning about what do we want when we're dying. And I think for me the most meaningful thing would be to be with people who recognize in me an essence beyond my body. Although I want competent medical care if I'm in a situation where I could utilize medical care, I still want that recognition. And I think there's a way that reality does get transcended when we have that sense of our own timelessness and our own essence.

When working with people who are grieving, I think the conversation does go on; it goes on very powerfully. I think there's some kind of communication, some working out of relationships in some way.

PARTICIPANT: Just a thought, a comment. I was moved by several things that people have just said. But I'm thinking back to this morning and Sandra Gilbert's metaphor of death's door, and the very powerful way in which she described how a door does seem to be open between the person who has died and someone who was close to him or her, and there's a very strong feeling of pull or attraction. And that's not something I have ever heard anyone talk about so vividly and compellingly, but I recognize it. I have felt this is true, I have felt that. I think one of the reasons for—I'm guessing—that part of the obsessionality about when does death occur, when can we be sure it has occurred, when is it finally over, may have to do with our anxiety about that door being open, and a need that we have to close it, to draw a clear line between death and life, the person who is gone and ourselves who have survived—in part, because it's scary, it's frightening, it's attractive. And if we're going to continue to live, we do need at some point somewhere, somehow to close the door. And I think that funeral practices and rituals, and art-making, also, thinking back to Jim Goldberg's presentation, are ways of closing the door, but closing it gently.

SANDRA GILBERT: Thank you for what you said, because I need every kind of affirmation that I can get. I hear two absolutely different strains of thought here, and I just want to go back a little bit and note that on the one hand there is a whole medical group of people, who are talking about death in a very medically-specific, culturally Western way, and then there is another group of people talking about representations of death, and mourning practices, beliefs about death and about the other world. And maybe one way of bringing this together is to remind ourselves that we shouldn't be quite so Euro-centric or Western-centric as we're being, but think about cross-cultural death practices.

I do not mean that death is a cultural construct. Everything, supposedly, is a cultural construct, but death just isn't. However, responses to death are. And there are certain things that seem to persist cross-culturally in ways in which people respond to death, a sense that the dead are sometimes present, that there are

openings into death, that the dead are either mournful or dangerous, or comforting, that the dead are somehow there on another side. I mean, there are cultures in which the dead are sent out with stones. There are cultures, on the other hand, where they are welcomed back in; I talked about some of that this morning. I wish there was some way that we could, in talking about seeing the difference, think, too, about cultural difference and think about the ways in which our own practices might be educated by the practices of other cultures.

TOM COLE: I want to try to offer some thoughts about the debate we've been having about death as a human passage versus death as a physiological fact, and whether there's a way of bridging the gap. I think I want to side with Michael Witmore and his discomfort with the formulation that just because we can't know death in any truly empirical way, that we don't take the images and intersubjective truths of our minds and our cultures seriously as a way of experiencing and understanding the death of others, or perhaps our own death. They're just not the same, the thing and the word. But it doesn't mean that we shouldn't take our words very seriously and our images very seriously. That's the part of what allows us to be human and continue to be human.

So I would say that one way of thinking about this dichotomy between death as a human passage or as a physiological event is to say that we should not look for universal abstract answers to a question like that. We should say who is dead, what's the situation, and for what purpose is the question being asked? Well, in the bereavement groups, it's very important for the survivors to be able to conceptualize, you know, caregivers to be able to think of things in human terms, I mean, experiential terms that are moderated by metaphor and language. But, in a cultural context and in medicine, it's also important to get the numbers right, so that if possible we can get the blood pressure up so that there could be oxygen to the brain, so that we can have the images.

GAIL GREEN: I'm a little concerned we've gone over the time, so, perhaps, probably we should continue the discussion tomorrow. I want to thank you all.

Session Three  
**Vision—Confronting the Margin**





# Editor's Note

## Session Three

How we look at the dying and at the dead is the focus of Session III, “Vision: Confronting the Margin.” LaVera Crawley, M.D., from the Stanford Center for Biomedical Ethics, introduces this portion of the institute by providing her own example of how an individual may or may not see the imminence of death: where the purely visual cues may be inadequate to what Jodi Halpern has called (in Session I) “acknowledgement.”

The tension between the scientific gaze and compassionate or empathic looking dominates the presentations and ensuing discussion in Session III. Historian Tom Cole, from the Institute for Medical Humanities at the University of Texas Medical Branch at Galveston, draws on Adam Smith’s *Theory of Moral Sentiments* to argue that we have a “relationship with [the dead] which is imaginative and no less real for that.” He then goes on to discuss—and show clips from—a film he is producing about that relationship; it shows the experience of medical students encountering the cadaver for the first time. How, the film asks, can one learn compassion in the anatomy lab? Can such experience help prepare medical students for the realization that, despite the powerful tools of their profession, there is no cure for mortality, the “inescapable condition of being human”?

Pathologist Frank Gonzalez-Crussi, from the Northwestern University School of Medicine and Children’s Memorial Hospital in Chicago (emeritus), is

also concerned with the body in death. Describing the role of the pathologist as emblematic of the “excessive reliance on optics to obtain knowledge,” Dr. Gonzalez-Crussi goes on to offer other notions of “seeing” in other cultural spaces and historical moments. The sight of the cadaver also poses a riddle, he says—particularly in Western cultures, it is a presence that is also an absence.

Commenting on Session III, Patricia Benner, Professor of Physiological Nursing at the University of California, San Francisco, remarks the contrast between the clinical entity of death and death as a “human passage,” labeling it a “dialogue between the Cartesian body and the social sentient body that dwells in real, finite, risky worlds.” Professor Benner recounts examples of “grief stories” from the world of critical care to argue for the importance of social relationships and personal interactions in the dying process, and for the limitations imposed by what she calls “choice” language in the discourses of death and dying as currently practiced.

Issues of discussion in Session III include: the risks of engagement for health professionals; a historical development that saw the rise of the power of the hospital and the instantiation of the medical (and funerary) establishment—over the family and community—as those who are “intimate with the dead”; the limited role of humanistic education in medical training; and contrasting notions of the body in death, especially as seen in literary traditions. —CMG

**Panel Chair:**  
**LaVera Crawley**  
**Stanford Center for Biomedical Ethics**

When I asked Tina Gillis what she envisioned in that topic and what she had in mind for us, she said she was interested in what we see when we're looking at that particular place, at the margin. She did not say what is the proper preposition to follow that—the margin within or between life and death.

As I tried to make meaning of that for myself, I thought about a case in an ethnography that I conducted on end of life issues, where we followed patients who were seriously ill with terminal disease or serious and complex illness where death was a possibility. And one patient came to mind whom I enrolled in my study, a young man with leukemia, who had a very poor prognosis at the time that I met him. He enrolled in the study, but unfortunately, even before I had the chance to do the in-depth interview with him, he died. Hence my first real deep visual encounter with him happened on the autopsy table. That was my first real intimate connection with him. Although two of our speakers today, Tom Cole and Frank Gonzalez-Crussi will be talking about encounters with the dead body, this is not the only reason this case comes to mind for me. What really brought that case to mind for me was the interview I conducted a year later with his mother, in which she struck me with the curious notion that even though she knew her son's diagnosis from the beginning and she was well aware of his prognosis, particularly as he got sicker and sicker and was failing chemotherapy, she said that she was completely, completely surprised when he died. And I couldn't reconcile this: "Well, if she knew his diagnosis-prognosis, why was she surprised?" I went

back to look at the text last night to refresh my memory about this and make sure I had it right. Her response was that she was surprised “Because he never looked like someone who was dying.” The visual cues for her were never there. So I think that’s how I have personally interpreted what Tina Gillis had in mind for today’s topic, “Vision: Confronting the Margin.”

**Thomas Cole**  
**Historian, Institute for Medical Humanities, University of Texas**  
**Medical Branch, Galveston**

What I'd like to do is talk to you under the rubric, more or less, of "Can one learn compassion in the anatomy lab?" I've been a teacher of the medical humanities for about eighteen years now. And when we teach first-year medical students, I'm always very uncomfortable with the lack of humanistic education that goes along with gross anatomy. For years, I said, "Well, we need to have a memorial service. We need to talk to them about how they're feeling; we need to help them imagine these people." And my colleagues just looked at me like I was nuts, especially the anatomists. But I basically decided that the most effective way to try to explore this was through the medium of film. And I have long been convinced that there's a deep relationship between the donor and the dissector. The basic idea of my film is to explore this relationship between the donors and the dissectors, with a notion that there's a lot that we can learn as mortals, as students, as teachers, and as donors. And I'm pleased to have the opportunity to show you about fifteen minutes of this work in progress that should be finished sometime next year.

I also wanted to pick up on some things we were talking about yesterday, about the relationship between the living and the dead, because in my graduate course we've been reading some Adam Smith recently, in particular, his *Theory of Moral Sentiments*. Smith is a much-overlooked figure, I think, in enlightenment thought. For us, he can help us bring together the connections between imagination and art and moral philosophy. He's basically a moral philosopher who said, "Look, you really have to pay attention to feelings and imagination and empathy." Let me read to you from the section in chapter one where he talks about sympathy

and the qualities of sympathy, and, in particular, sympathy with the dead. I think there will be a lot of resonance between this passage and the discussion yesterday.

To sympathize even with the dead in overlooking what is of real importance in their situation, that awful futurity which awaits them, we are chiefly affected by those circumstances which strike our senses, but can have no influence on their happiness. It is miserable, we think, to be deprived of the light of the sun, to be shut out from life and conversation, to be laid in the cold grave, a prey to corruption and the reptiles of the earth, to be no more thought of in this world but to be obliterated in a little time from the affections and almost from the memory of their dearest friends and relations. Surely, we imagine we can never feel too much from those who have suffered so dreadful a calamity. The tribute of our fellow feeling seems doubly due to them now when they are in danger of being forgot by everybody. And by the vain honors which we pay to their memory, we endeavor for our own misery artificially to keep alive our melancholy remembrance of their misfortune. That our sympathy can afford them no consolation seems to be an addition to their calamity, and to think that all we can do is unavailing, and that what alleviates all other distress that we grant the love and the lamentation of their friends can yield no comfort to them. It serves only to exacerbate our sense of misery. The happiness of the dead, however, most assuredly is affected by none of these circumstances, nor is it the thought of those things which can ever disturb the profound security of their repose.

The idea of that dreary and endless melancholy, which the fancy naturally ascribes to their condition, arises altogether from our joining to the change which has been produced upon them, our own consciousness of that change—from our putting ourselves in their situation and from our lodging, if I may be allowed to say so, our own living souls in their animated bodies,

and thence conceiving what would be our motions in this case. It is this very illusion of the imagination, the foresight of our own disillusion, that is so terrible to us, and that the idea of those circumstances which undoubtedly can give us no pain when we are dead makes us miserable when we are alive. From thence arises one of the most important principles in human nature, the dread of death, the great poison to the happiness, but the great restraint upon the injustice of mankind, which while it afflicts and mortifies the individual, guards and protects the society.

This is an interesting rumination on some of the issues that we talked about yesterday, particularly the realization that there's a cold face of the person who is dead, whose future we can't really affect in any way; and we have a relationship with them which is imaginative and no less real for that. It makes us frightened, and it makes us better people for that—it gives us restraint; it gives us a sense of caution.

So what I'd like to do now is read you a kind of prologue and then show you a clip of the film, and then we can talk about it during the discussion period. This prologue is what I read to students in the anatomy lab to set the mood for the discussion I want to have with them. It's very hard to talk about these issues. And, of course, these are students who have to get through the next practicum; they have to learn every artery and every nerve that their anatomy instructors insist on. And they will probably be resistant to questions like, "What's your relationship to this person? Who were they? How do you feel about this? Did you imagine your own death? What do you think this person was going through at the end of his or her life?"

The premise of this film is that the dead have a great deal to teach us. But we must open our hearts wider to receive their wisdom. People who donate their bodies to science have much to teach us beyond yielding up the intricate structures of their bodies. They can teach us about life, about what it means to be human, but only if we are willing to ask questions which are emotionally and spiritually as intimate as the physical delving,

cutting, looking, pulling, sawing, and slicing that takes place in the anatomy lab. Learning in the anatomy lab is usually limited to knowledge obtained by careful dissection, observation and memorization. Perhaps learning compassion can also begin in the anatomy lab, where a cadaver is the first human body encountered in medical education.

Is the cadaver a human being? What is the proper attitude to take towards someone who has died? Respect, said Freud, for a person who has accomplished a difficult task. How do we show respect to a dead person's body? Can a cadaver be respected? Can it be harmed? Can one show compassion for a cadaver? No, compassion is a disposition towards people or creatures who suffer. Cadavers don't suffer. Do their spirits, their souls, their ghosts? My head says no. My heart says yes, of course.

How can one learn compassion in the anatomy lab? First, by daring to feel the awful truth, that each one of us will some day be equally dead. Second, by realizing that this cadaver was once as full of life, joy, and pain as we are today. Third, by realizing that while medicine has developed powerful tools of prevention, diagnosis and cure, there is no cure for mortality, that inescapable condition of being human. And, fourth, by appreciating the gift received from the person who willed their body to science so that we can learn. Compassion, then, may flow from wrestling with these existential questions, learning to connect anatomical knowledge with personal powerlessness. Is this too much to expect of students beginning their medical education? Yes, but it is not too much to expect them to begin this journey to give themselves knowledge.

[Professor Cole then went on to show clips from the film in progress. The following comments are made by medical students in the film.]

This is the first time I felt that this was actually a different person and that someday I would die. I've never been around the

dead, all my family is all alive. This is the first time I've actually experienced death.

I saw the cancer that had taken over her stomach and her colon. And I thought, "What was she going through the very last couple of hours? Was she sitting, was she lying down, was she feeling any pain?" That's what I started thinking about, about how she was when she was alive.

The more I think that this was a living person, it kind of scares me. So I kind of try to shut it out as much as possible. The less I think that this was a living person, I think the more comfortable I become, and the more I can just come in and focus on what I can do.

Our cadaver died of colon cancer. And I saw a bit of what she possibly could have been going through because my grandmother died of pancreatic cancer about four months ago. And the only thing that allowed me to come grips with it is that in the Christian religion, the body is deemed as a vessel, and we're only borrowing it. We had to slice through the spine. I had to do it because I had told myself that this was just a vessel. We do this, you know, so we can continue to learn. Now, there were thoughts that, "Man, what if you were doing this to a living human? You would be causing extreme pain."

I felt that [the cadaver was] saying, "Okay, you can do it." It helps me to come to terms and be able to be okay with it and say, "They wanted me to do this."

Well, I'd say the body was beautiful, but I usually associate beauty with romance, and there's absolutely nothing romantic about it at all, either in its purpose or in its color, anything. But it was

beautiful in the sense that there was just an absolutely amazing order to everything. And that kind of order is like a gothic cathedral. It's as if somebody tells you, "Look, you go into the first room on the right and you're going to find this nice little wooden treasure box."

When you see, for example, *The History of Surgery*, you see these idealized drawings of cutting up cadavers. But when you actually get in here, there's no art to it.

The most amazing image I have of having the experience is of one of the members of our group standing over the body—it's already fairly well protected—with a saw. It was the most dehumanizing aspect of it. This really was a person. And the image really drove it home to me, how much this was really just a body now, just parts.

I would say thank you to the person for giving us her body to study. But I would also feel horrible knowing what goes on to the bodies once they're in here. It would be hard to face her knowing what we did.

What else can you do? Do to the best of your knowledge; work in what you have to do; learn something from your body.

I wish there was a better way of knowing it besides the total dismantling of a body. When you throw away a large body part into the buckets, or the trash can, essentially, that's very disturbing.

It's sad... to me it is. To me it's sad every time we dump ashes. So many people. I just wondered if you heard them talking, what would they be saying or what would they be thinking?

This remark came from an instructor:

The students took the cover off the cadaver. The first thing they noticed is how young he was. And one of the students said, “I wonder what he was like?” I told him, “He was a nice guy, and you better learn a lot of anatomy from him.”

**Frank Gonzalez-Crussi, M.D.**  
**Pathologist, Children's Memorial Hospital, Chicago**

I was greatly intrigued when Christina Gillis first told me that she planned an institute on death, and that the title that she was considering was *Seeing the Difference*. What I found most provocative was the word seeing used in the title; I have good cause to be sensitive to this appellation. For one thing, seeing has occupied a very large part of my life; as a practicing pathologist, seeing is what I have done for a living. Moreover, the pathologist's gaze must, sooner or later, rest upon the dead. To see, to look, to inspect, to study visually, either through a microscope or with the naked eye: this activity has been my livelihood for nearly forty years.

I would add that my dependency upon the visual function was complete and unrestricted. Had I been unable to hear, to smell or to taste, I could still do my job quite well. Had I been impaired in my capacity to speak, or to move, it would have been a great personal tragedy for me, but not with reference to my skills as a diagnostic pathologist. These would have remained intact, so long as I could continue to be able to see, to think and to remember. My job is therefore emblematic, in a way, of what is now fashionable to call "oculocentrism": excessive reliance on optics to obtain knowledge. This constitutes both the strength and the weakness of my job. It is also a thorn in the side of epistemological discourse in Western civilization. As you know, the notion that knowledge of the nature of reality can be acquired simply by looking, the "spectator concept of epistemology," as John Dewey called it, has come under harsh criticism.

But it is not my role—fortunately—to discuss arduous philosophical questions. I simply wished to set into relief the heavy load of significations in the title *Seeing the Difference*. Especially so when the topic is death. What is the “difference” being alluded to? Is it the difference that we see between the living and the dead? Or is it the different forms of seeing or understanding death? (For “seeing” is metaphorically used to mean “understanding” in everyday life. We say “I see, I see” when we finally understand, and we “overlook” when something escapes our notice.)

Let me, first, take “seeing” in an entirely literal sense. Thus, I should interpret the meaning of “seeing death” as, rather, “seeing the dead.” This is always a complex act, subject to various interpretations, stemming from different motives, and yielding diverse perceptions. The sight of a cadaver is both avoided and sought. It exerts a unique, ambivalent fascination. It attracts and repels at the same time. The sight of a dead person hands us an obscure premonition of our own future dissolution. Thus, the presence of a cadaver carries that morbid fascination that one experiences at the edge of a precipice. Our instinct is to flee, but there is also a pull towards the void. The result is an ambiguous sensation of double valence, an anguishing kind of contradiction, a sort of metaphysical vertigo.

The sight of a cadaver poses a riddle. It has been said, using a technical and somewhat pretentious language, that “the corpse remains as an empty signifier devoid of its phenomenal causation.” In plain English, we see a presence that remits us to an absence. For we see someone who is no longer there, who has already departed. But perhaps we should correct this statement, and say that we see not someone, but something. The awful, indescribable transition from person to decomposing lump of matter has already been accomplished. This is what the sight of a cadaver reminds us of, either consciously or subliminally.

But I have commented here, in this institute, that there is no possible description of death. There are no words in the English language, or any language, that may express what has happened. It is not right to say “change” because change implies continuity, and in death there is no continuity: it was John or Mary last night, or a few minutes ago, and now it is a piece of decomposing organic matter. This is not a change, as happens in aging, or weight loss, or

changing one's shirt. This is transmutation of a completely different order, immeasurable and incomparable, whose nature utterly escapes us

Thus, the presence of the cadaver is fundamentally paradoxical. It is a presence which is also an absence. This is why the absence of a cadaver is doubly distressing. The presence of the corpse is essential for the relatives and the loved ones who survive. They must perform the funeral rites, whose goal is to fill the void of the absence that they experience. In preliterate societies, to die far away from home is often thought to be the worst kind of death. It is hurtful to the one who dies, and to those who survive: to the one who dies, because he shall be deprived of the funeral rites, which ensure his proper accession to a peaceful afterlife; to the survivors, because they will suffer a perturbation of the social order. The dearly departed who is not there cannot be seen, cannot be symbolically questioned. One cannot make confessions, address reproaches, or elicit common souvenirs with the absent. This is why a badly disfigured cadaver is, in this regard, equivalent to an absent one: it cannot be identified. Thus, a man who dies away from his loved ones is doubly absent: absent because he is dead, and absent again because he is not physically—corporeally—present. This is an absence of an absence, an absence with an exponent, an absence to the second power.

To avoid this twice-tragic fate, various human societies have devised fake burials: ceremonies in which a substitute, a symbolic corpse is buried. This may be a garment of the deceased, an effigy of the same, or a ritual object of some kind. The cenotaph may be the refined, European equivalent of these customs: it is a monument to a dead person whose cadaver is not there, but elsewhere. The same metonymic principles seem to be invoked in a European cenotaph, and in the fake burial of a preliterate society.

Therefore, seeing the dead is always ambivalent. It is a sight that we avoid, as the all-too-obtrusive reminder of the precariousness of our own life. It is also a sight that we seek, as the only concrete reality on which we can anchor the illusion of a living presence. We know it is only a mass of quickly decomposing proteins, but it is the only material form of a presence that we used to love, and thus we are ready to invest it with personal attributes. This is how the sight of the dead is yearned for, that we can address to them a last farewell, and that they can continue

to exist in our gaze for yet a little longer. That we can keep on seeing them for a while.

Seeing the human attributes in the dead, seeing the humanity in the corpse as something that is inseparable of the corporeal form, is inevitable. It is automatic in all of us. This is why the workers at the morgue, the dissectors, like the embalmers who must open the body of the dead, instinctively cover the face of the cadaver. It is unsettling to contemplate the face of the dead while performing, on their bodies, a troubling act that is something of a desecration.

There are other motives, some of dubious nature, for seeing the dead. In the course of my professional years, I was approached by numerous persons, from many walks of life, for permission to watch an autopsy. I found it difficult to understand why they wished to see a cadaver being dissected. It was easy to agree that, for nurses or medical students, this was part of their professional schooling. But many others had insufficient justification. I was often compelled to deny them permission to enter the autopsy room. Throughout the years, I had requests from technicians, photographers, lawyers, amateur artists, journalists, and even hospital secretaries. On one occasion, hospital security guards approached me for permission to watch an autopsy, under pretense of instruction. I found out later that, during a private party, after much spiritous libation, the security men had crossed bets among themselves, as to who would be courageous enough to witness a cadaver's evisceration without flinching. Another incident, equally childish, concerned night shift employees of hospital administration, who made it a test of courage to come to the morgue alone, in the dark, armed with only a flashlight, to open the refrigerators where cadavers are kept. The morgue of the hospital was located in a remote, usually deserted part of the building. Seeing the dead seemed to have been, in these cases, a test of mettle, or perhaps some form of ritual fazing, or childish initiation ceremony.

And what are we to think of seeing the dead as sheer spectacle? The idea may shock contemporary sensibilities, but not too long ago, in the city of Paris, the morgue functioned as an institution of theatrical display, as a form of entertainment. Ostensibly, the reason for exhibiting cadavers to the public was that those individuals who died in the public domain, away from home, could be identified by their friends, relatives and acquaintances. The social order would

thus be preserved, and the appropriate manner of burial and grieving could take place. But against these professed, laudable social ends, the administrators of the Parisian morgue could not have predicted that their institution was to become the best show in town: public theater, open to the public from dawn to dusk. And best of all, it was free.

The description is familiar to many of you. Cadavers were placed on slabs, naked except for modesty-inspired covering of the genital area, behind large glass windows that could not have failed to evoke the large windows of department stores, which at the time were just beginning to appear and to displace the small family businesses. The crowds of watchers, people from all walks of life, young and old, pressed against the windows, and manifested their displeasure when the slabs were empty and there was nothing to see. If the registrar came to evacuate the exhibit room, he was apt to hear loud complaints, even insults, from an irate public that protested against the sudden closure of the spectacle. The best description of this, in my opinion, is offered by Emile Zola in his masterful novel *Thérèse Raquin*. He tells us of groups of workers that wander in at lunch time with the instruments of their trade under their arms; retirees who come to watch the corpses because they find nothing better to do; rowdy schoolboys who shout catcalls and invent nicknames for the cadavers; and elegant ladies, one of whom Zola describes watching the naked body of a statuesque construction worker who had succumbed in an accident on the job. There is an intimation of sickly erotic undertones in the gaze of this watcher. Zola reminds us, in this passage, that seeing the dead is indeed different, depending on who does the seeing.

Enormous crowds visited the Paris morgue in those days. Up to 40,000 persons in one day. The Thomas Cook tour of the city included a stop at the morgue. English tourists were particularly interested, presumably because there was no such spectacle in London. Or so they said. Every guide book listed the morgue. As Vanessa Schwartz points out in her interesting scholarly work on this Parisian institution, it is puzzling to consider why, in a city that certainly did not lack visual attractions, such a vast number of people (a million in one year, according to estimates of a contemporary newspaper) opted to crowd the *salle d'exposition*, the exhibition hall, of the city morgue, to watch the cadavers of people who had died an unexpected, often violent death.

Be that as it may, the Paris morgue was finally closed to the public. The decree of its closure came as late as 1907. A campaign against the public exhibition of cadavers had started long before—not on account of hygienic considerations or medical concepts, but based strictly on moral principles. The keeping of cadavers in view of the public, and in proximity to the crowds, was condemned because, according to an important sector of the bourgeoisie, it was disrespectful to the dead, and potentially capable of arousing the base instincts of the people. Critics of the morgue called it a “bloody spectacle,” and opposed it on the same grounds as the spectacle of public executions, namely, because harrowing spectacles of that sort would stir the shady part of the soul, might excite cruel and barbarous feelings, and thereby would increase crime.

What one may actually perceive in the spectacle of death depends on the individual. Seeing is invariably in the eye of the beholder. I shall briefly refer to two styles of seeing that I may call “culturally dependent,” for lack of a better term. In the traditional Mexican culture, which is permeated by a strong current of Indian naturalism, death is something very concrete. I am not an anthropologist, but this much I can say from my subjective impressions during my youth: death in Mexico is always embodied. Death is this cadaver, right here. It is something that may be palpated, touched, weighed, turned around. I was always impressed by the directness with which the survivors addressed the cadaver during a funeral ceremony in the lower socio-economic strata. There is much display of emotion, and the bereaved talk to the deceased. It is a new form of relationship. The survivors speak to the dead person: they reproach him for having left this world; they remind him of the joys and sorrows that they shared together; they make confessions, grant absolutions or admit having wronged him; and they promise him that they will remember him forever. They talk to him, not at him. I am sure that, if these addresses were only monologues, they were the kind of monologue that absolutely required the presence of the cadaver as mediator of the monologizing. The present-absent is much more present than absent, if I may thus express this unique status. In other words, the corporeal reality of the departed is strongly felt. It is a powerful sign that propitiates the illusion that the dead are still with us. Death is primarily a presence.

When the dead are deprived of their corporal wrappings—the flesh, the nerves, the arteries (by now utterly superfluous)—there remains the skeleton. The

skeleton is the almost universal emblem of death. But because it is eminently tangible and concrete—solid, stone-like—it has had a great career in Mexico. In the Mexican culture, the symbolic skeleton, the *calavera*, is not only felt, palpated, and even played with, but is also tasted, in the form of the sugar skulls that are consumed on All Souls Day, the day of the dead. For it is not only recent death that has a presence. Death is recurrently present, eminently present in the mind, at least on All Souls Day the *Día de Muertos*, the “Day of the Dead,” year after year.

It is otherwise for cultures in which death is primarily an absence or a disappearance. In one philosophical tradition of Anglo-American culture, the living person is easily destroyed. Recall that John Locke says that personal identity is “inseparable from thinking,” a mere consciousness displaying unity across time. And David Hume saw the person as “a train of perceptions” glued together by certain relations. Consciousness must attach itself to an animal body, or, as we say today more specifically, to a functioning brain. But body and brain were secondary, and in a sense irrelevant. Consciousness alone conferred identity. Consciousness alone embodied the essence of personhood.

But if the person is merely a precarious bundle of mental activities, the dead person must be flimsier yet. The “Great Iceberg of Cotton Wool” of which Henri Michaux speaks in one of his poems, can erase all traces of the person. Death thus becomes an erasure, that is to say a disappearance, an absence, or a mere attribute of the insubstantial mind, of the fleeting consciousness, like the person itself. Not a concrete osseous framework—as is the Mexican skeleton, the *calavera*—but a wholly immaterial entity. Defined as an absence, it absented itself. Because it could not be seen, it ended up suffering the fate announced in the popular saying “Out of sight, out of mind.” It was proscribed, and it became the Unmentionable.

To finish these comments, I wish to say that I believe there is a parallel between the death-related Mexican naturalism, and—strange to recount—certain ideas that I have found in the pages of Russian novelists. It has been remarked that Tolstoy never approached death as a philosophical problem. He never seems to be looking for comprehensive concepts, conclusions, or intellectual approaches to death. He is not striving to create a philosophy of death; he is merely describing the experience of living beings.

Since death cannot be understood, conceptualized, reduced to system, or dealt with syllogistically, the only thing left is to look at it. Such is the gist of the Mexican attitude. The gaze will not penetrate to the essence of the problem. It will barely skim its surface, but that is all we can do. And this is what Tolstoy does: to describe tirelessly, to evoke every detail of the external corporeality of death, to all the minutiae. Read the last pages of *Ivan Ilyich*, to find there a recreation of every sensory impression, the sounds, the sights, the odors that impressed a child. Vladimir Jankelevitch points out that this is one constant throughout the whole Tolstoyan work. He revels in the details, in the concrete particularities.

Tolstoy's objectivity is a clinical objectivity. I venture to say that he must have been like one of those physicians that Guy Micco told us about yesterday, who can tell precisely when a person is dying. In *Three Deaths*, one of his unexcelled short stories, he observes of one of the dying personages that "she had that attentive and concentrated gaze of the dying." In *Anna Karenina*, when narrating the death of Nicolas Levine, he writes: "He looked straight out before him, with the same tense and concentrated expression." Turgenev's *Diary of a Superfluous Man*, contains very similar observations: the diarist tells us, in a line or two, how the eyes of his dying father seemed fixed. The meticulous observations of Russian writers lead us to believe that those who die are seeing something. They seem attentive. What do they see? Certainly not their immediate surroundings. Not the objects of the mortuary chamber close by, but something else, something remote, infinitely distant. But what this may be, neither Tolstoy, nor you or I, can ever know. For as long as we live, we shall be condemned never to know.

## Comment

**Patricia Benner, R.N., Ph.D.**

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I'm really struck by and surprised by the conference. We came to speak of dying and death. We have been confronted with perhaps the hallmark of disengaged reasoning in the cadaver. Even in Tom Cole's attempt to reanimate the relationship between the donor who wanted to contribute to the community, and to science, and to better future lives, there is a way in which we can't overcome the very real symbol of disengaged reasoning and the body laid bare in the cadaver. Some of us talked a little bit last night about all the silences in the conference. And there is this silence of world and embodiment because to die is to lose one's human world. And none of us knows really what that's like for the one dying. But for those of us who are left, but have lost a world-defining, self-defining relationship with the one who dies—as Sandra Gilbert has so profoundly confronted us with in talking about the death of her husband—we have lost our world; our world will never, ever been the same.

So there's something really profound that I hope we can capture in our thinking together about our fascination with the clinical gaze and the cadaver, with the clinical entity of death, and death as a human passage. I didn't know this conference would take this turn, this dialogue between the Cartesian body and the social sentient body that dwells in real, finite, risky worlds.

I was very moved by Jim Goldberg's picture of the bed and the chair, in the very last hours with his father. And I understand that chair as being symbolic of the capacity to dwell. Even when you're reduced to bed and chair. A longing to

move, even from the bed to the chair as a last act, is really profound. And then the chair is empty and he cannot get his father to the chair. And that sounds like, smells like, feels like many deaths I've observed.

Instead of the metaphor being ocular-centric, I think it is more as Tolstoy would have us envision it, that it is about touch and smell and world. We are so oblivious to what constitutes us and what constitutes a world for us, and how dependent we all are on each other to hold open the world. And how hard it is when you're dying to have all your horizons cut short, and not to be able to imagine a future. That's so difficult that we escape from it and we—I say “we,” I think of all the people that I've been with who were dying—keep trying to find a way to imagine a horizon just a little further open.

This was another thing I was struck by in Jim's comments about Fran, the love object, the intimate stranger, the compassionate stranger, who comes in, in this free relationship to laugh and to joke and to pay attention to favorite drinks and positions and the very physical world in a way that sometimes family cannot do simply because they are losing their world. There is a bit of anger, there is a real tug of war of letting go, and we have this incredible cultural invention of the compassionate stranger, who would come and who would talk about ordinary things. For me, there is the case of Mr. Baker, whom I met when I was nineteen years old. I had known his wife very well, worked with her in the office, and here I was learning to be a nurse. And he said, “Well, because you're a nurse you can bear this.” I was nineteen years old, give me a break! I thought, “How can I be with Mr. Baker, and I love Mrs. Baker.” I knew I had nothing to offer. And it was in the early death awareness era, when we were not going to keep it a secret anymore. What Mr. Baker taught me was that he still liked his coffee really hot. He liked his bed where he could see the sunset. He wanted a flower where he could see it. He wished he could go home one more time. And he still liked a good joke. So there is this thing about what it is to have a world that we confront in facing death and being with the dying.

Sandra, what I learned from you is this profound love, in an honest raging against this stupid error that took Elliot from you. Kierkegaard's great vision of grieving is that when you lose a self-defining relationship, a world-holding-open relationship, you find a way to take up life and have the courage to engage in new risky commitments that might also die: you won't just imagine that

the loved one is there with you, you will acknowledge that he is indeed dead. You will find a way to put your life together that honors that self-defining relationship but has the courage to risk loving again and maybe losing another world because dying is always about losing a world.

I have several grief stories I want to share and then we'll open for discussion. My goal is to revisit the way in which, when I say death is a human passage, I'm not talking about transition. I'm talking about the human passages like birth and marriage and divorce and losing your job, those kinds of human passages where one world passes away and you have to find your way around in a not-yet-understood world. And I've been, for the last eight years, studying Critical Care Units, where I've come to observe the makeshift rituals that people pick up from the fragments of whatever cultural conglomerations they can pull from our American culture. The following is a story of a retired man, his wife, family and grandchildren at the time of his death, and the rituals of reminiscing and narrative reflection of a life come through.

The nurse in the case tells the story:

I received him from the regular unit about 3 o'clock in the afternoon, so I took care of him for about four hours that day. Then the next morning, when I came in to report, they had just intubated him. By the time I got out of report, they were setting up and putting basic lines in, and by 10:30 in the morning, he was being dialyzed. So all of this happened in the space of about five hours. It really kind of overpowered this man, who was still quite with it. He knew everything that was going on, even though his liver enzymes were sky high. I really thought that he should have been encephalopathic by then, but he wasn't. And his family was all there, really kind, and kind of in more control than I think my family would be. But what happened through the day is that none of these interventions made any difference in his lab work, none of it made any difference in his clinical picture. He continued to deteriorate, and after being on dialysis for four hours and not having that make any difference at all, his wife and family said, "It's time to stop." At that point, this was the first time I

had ever said this to a patient. I said, “You’re going to be taken off dialysis and you’re probably going to die within a couple of hours.” There is an awesomeness of saying that to someone. I knew he could hear me, he responded to me. And his eyes just kind of popped open, and then this peaceful look came over his face. It was an amazing transition.

Second nurse: Did you really know he was going to die in a couple hours?

First Nurse: Yes.

And I must say we seldom really know this, but this was one of those moments.

Second Nurse: Medically, it wasn’t intuition?

First Nurse: It was not intuition, he had total body failure. It was the first time I had ever been able to say that to a patient. I had only met him the night before, but it seemed like we had connected in some way. It felt like there was—I don’t want to say a relationship, that sounds much too deep—a rapport, a connection.

And it’s this kind of connection that the intimate stranger can have, as one who can be in common humanity with someone who is dying, who goes home to an intact world. That’s an amazing cultural invention; let’s not downsize that too far.

First Nurse: Something between him and me. But this was a case that was obvious, it was clear. One thing I did want to say about that whole situation is that I felt very possessive about him, about everything that was going on with him. He was a one-to-one patient. I didn’t have to deal with any other patients in the whole unit, and I didn’t.

Third Nurse: I remember that day. You sure didn’t. We didn’t see you. You ran your legs off the entire day.

First Nurse: But I wanted it that way, I didn't want any other nurses in there with me, I wanted to deal with Dr. S and J and T, who was in there doing the dialysis.

Interviewer: When this situation changed and he was now dying, did you do anything in terms of managing the environment?

First Nurse: I felt a great urgency to get all the peripheral junk out of the room, as many machines as possible. It had been noisy in the room all day, and I wanted to try to get the noise level down. Get some chairs in there, just different accoutrements in the room. Instead of having all this technical equipment in there, just to get rid of all that as much as possible, leaving just one IV pole to pump the ventilator, and kind of hiding the arterial and pulmonary lines. And then setting the room up with some chairs, and making sure there were several strategically placed boxes of Kleenex, and his water pitcher, and several glasses. All his family was there—his grandchildren were there, everybody was in the room, it was nice. We were off in one of the corner rooms, where we could close the door and nobody needed to bother us for anything. And I would leave the family for about, say, half-hour periods and just kind of keep my ear out for what was going on, and keep an eye on the monitor. I'd go back occasionally to see how everybody was doing. After, say, about two hours, the family started talking about him, not quite in the past, but, "Oh, you know what we did last year? It was really fun." Starting to reminisce a little bit and maybe work through some of their grief.

He finally died about 6:30 in the evening. To have been with him all through that really very critical period, making sure that he knew everything that was going on, making sure that his family knew what was going on during that critical period, and to help him into the most peaceful death that could happen un-

der those circumstances, gave me a feeling that I had really helped in that situation.

Well, I think that's a good contrast between death as a clinical event and death as human passage. And maybe it is the task of humanities to open up the social sentient spaces as human passage.

I want to contrast that with just one really brief situation, because it picks up the thread that we were following yesterday: how much consciousness do we want in facing our demise? Do we really want to know? How much do we want to know? This nurse seemed to be attuned. In that situation, this person really did want to know, and it would have been a kind of theft not to convey that.

In this situation, with a different patient, a different nurse, a nurse says, "I was standing at the bedside the whole time and he started having trouble breathing. And I was just cradling his head. And it is not my practice to lie to patients. On the other hand, to me this was just trying to get him through it." She refers to the calming and reassuring phrases that she was using.

But obviously he was having trouble breathing. The color was terrible around his face, except he kept going in and out of consciousness. My main task at that point was—I wasn't having to push meds or do anything else, or talk about the patient—I just sat there and held his head and held his hand, and talked to him until he wasn't hearing anymore. I just sat there and he ultimately died. I remembered thinking I should have gloves on. But it's terrible for someone who needs comfort so badly, and to have somebody who has gloves on hold his head with gloves. I just remember thinking that my most important task at that point was to hold onto him because no one else could do it. He was so awake and gasping for breath, he needed someone to comfort him.

But she felt conflicted because the situation was moving so fast, she was having to respond with comfort. And this kind of story always reminds me of how

difficult it is in ethics when we only have a language of justification, we only have a language of decisional ethics, and we have very little language for action, for being with, for relationship.

From a contractual vision of meeting autonomous strangers, we do not think of ourselves as being constituted by others, and tend to think of the moral self as that which is owned by the self and freely chosen. Care, connectedness, responsiveness and interdependence are signs of a moral lapse and are sources of embarrassment for the strictly autonomous atomistic vision of the individual, of this individual who is this self-possessed. For the autonomous choice-maker, care and caring practices can seem as yet one more set of choices until the position of caring and needing care intrude because care always implies situated or bounded choice. I mean, it is bizarre that much of the language of death and dying is so colonized by choice language, as if it is a choice or we're really ever able to confront it as a choice.

In intimate spheres, loving a child or a parent, such relationships preclude freely choosing to stop caring about the parent or the child, though one may physically separate from the other. In less intimate spheres, when one is vulnerable or incapacitated, choices about being cared for and receptivity to care are constrained. Care, publicly and privately, are bound up with the human condition. The thing that I would like to bring to the conversation, as a nurse, is the way in which our care both holds open and closes down worlds. Now that morbidity is expensive and mortality is cheap, there is a new ethical landscape in which we discuss death and dying. I think we need the humanities to help open up for us death as human passage and our ongoing social responsibility for constituting livable worlds for those with whom we live and with whom we might face death.

### **Session Three: Vision—Confronting the Margin Discussion**

THOMAS COLE: I had a question for you, Pat, because your language of “care holding open the world” reminded me of Sandra’s metaphor for opening the door of death. You began by saying that we can’t overcome the cadaver, the very symbol of disengaged reason. And I wanted to ask you, as a nurse, what it was like to be taught to care for a newly dead person? You must have gone through that. And do you think it’s possible to care for a cadaver in a way that is not inherently disrespectful? Some of our medical students say that the enterprise is inherently wrong, that it’s inherently disrespectful to break apart violently the integrity of the human body. I just wondered what you thought about that.

PATRICIA BENNER: I think if we have a very destructive, disrespectful attitude towards a stranger’s body, we also chip away at our own sense of integrity and wholeness. The relational ethic with the cadaver is a really important point.

The film Tom Cole showed us was very powerful in showing the need to disengage and the need not to dehumanize, although in some cases the fascination with being allowed to do what most ordinary people aren’t allowed to do comes through. I don’t know what to do with that. Western medicine gets so much of its power and vision and efficacy from laying the body bare and from the clinical gaze and from disengagement; and it is currently so silent about the middle terms of the lived life, the social sentient body, the body inscribed with meanings. Being able to find a way to get those middle terms, I think, is very important intellectual work that medicine needs to be doing. And there is something really

profound about the practice of dissection that is the perfect enactment of the disengaged reasoning and the treating of the body as unensouled and unworlded and wholly other.

BETTY DAVIS: I just wanted to comment about the idea of disengagement. As you were talking, I had the thought that there are different forms of disengagement or different patterns of disengagement. It seems to me that when a nurse or a physician disengages from the body or from doing any unpleasant task without thinking about the task, that the disengagement becomes a kind of defense mechanism to enable her or him to cope with having to do the task. And that's when the element of personalization or depersonalization occurs. But if we can say, "This was a human person, and let me respect what this person was, but I still have to disengage from this; I have to separate myself from this in order to be able to do it," then that seems to be a different kind of disengagement.

PATRICIA BENNER: I don't imagine that any of us can get by without the skills of disengagement. But I think that what we want also to learn more about are the skills of engagement. And those are very tricky—not to be over-identified, not to be over-involved. It is incredibly difficult to be the intimate stranger and compassionate stranger in a way that doesn't assume powers that you don't have as a helper, to learn the techniques that are not intrusive. It seems that we need to be able to talk about appropriate disengagement but the positive project remains learning the skills of engagement, the skills of involvement.

TOM COLE: I just want to follow up on that. Another way of thinking about this is, again, to avoid thinking in either/or categories, but to be aware of the necessity of a kind of double movement of consciousness and feeling that depends on what is happening in the moment. In Buberian terms we can talk about the difference between I/it and I/thou relationships. One of the rabbis at my temple thinks that the goal of a good life is to always be in an I/thou relationship. I said to him, "I just don't think that's feasible. You can't always lay your heart open and treat the other person as an autonomous loving self, with whom you reciprocate, because there's just too much work to do in the world. You sometimes have to shake hands and go on your way to the next person."

Another way to think about this is the image of spectator that you were referring to. I had a couple thoughts about that. The anatomical theatres of an early modern era were galleries where people came to view spectacles of dissection. But Adam Smith's ideal of the "impartial spectator" is a person who is capable of good moral deliberation. And the impartial spectator is sympathetic, feels himself or herself linked to others, to the dead and is able to move back into a reflective, more rational mode for decision-making purposes on evaluation. So I think we're talking about moving back and forth constantly, depending on what the other person needs, what the situation demands and what we need. And it takes a lifetime to learn that.

PATRICIA BENNER: I agree, as long as we don't imagine that that atomistic, separate autonomous self is the starting point. The big misconception is to imagine that we start as erratically independent, separate, autonomous beings and then we connect with others, as opposed to the idea that we are constituted by the connections.

And the other problem I have with both Adam Smith and Kant is that any emotional affinity has to be held in total suspicion and can't count as moral action; rather, what counts as moral for Kant, like Adam Smith, is this reflected, detached, imaginative private consciousness that stands over against private consciousnesses. This is opposed to imagining that one is co-constituted by the social spaces of relationship and that the relationships themselves open up moral possibilities. Moral perception may be dependent on relational skills and emotional affinities. If one doesn't have the schooling of being a loved child or a loving child, maybe many moral possibilities are always going to be closed down to one. And so to imagine that the moral pinnacle is this very privileged, deprived view of the separate, autonomous, reflective intellectual or pure will, I think, is false and misguided.

GARY LADERMAN: A word that came up several times and offers a rich kind of concept in thinking about all this is "intimacy": intimacy with death and intimacy with the dead. I tend to think historically about how that intimacy with death has changed over time and in America. In the nineteenth century most Americans were intimate with death. It was very much a fact of life, and we were intimate with corpses because bodies were at home, people died at home, and the death-

bed scene is one of the key cultural scripts that we have with which to think about the good death and the meaning of death. That intimacy was familial and communal and religious, in terms of who was really intimate with the dying and then with the dead body.

The first part of my book is called, “Intimacy Lost,” and the second part is called “Intimacy Regained.” I look at—I’m going back to the denial thesis—the many kinds of conflicting, contradictory, opposing social forces at work in the first part of the twentieth century, and how we lost that older sense of intimacy with the rise of hospitals and the conception that those who are intimate with the dead are doctors, nurses, the medical establishment, and funeral directors. Religion has kind of disappeared. We have a broader split wherein religion is associated with what is supposed to continue after death, a kind of imaginative and spiritual looking at what happens to the soul, whereas the body is left for the new specialists who acquire the kind of intimacy of doctors who are opening up corpses or funeral directors who are embalming them. And in spite of the kind of talk we’re hearing today there’s a sense in which the history of medicine is founded on this kind of clinical gaze.

So in reference to the medical students who are opening up those cadavers, I see a kind of struggle with being intimate with the corpse. You can only be intimate, I think, with a living thing.

FRANK GONZALEZ-CRUSSI: I think that we should remain open to the various styles of thinking, with respect to just exactly what kind of deference or what kind of respect is owed to the dead, and whether that would preclude dissection or not. I know that in the Christian tradition the body is something despicable, a vessel of rottenness. We are dust and shall return to dust. Not much respect was owed.

And if that kind of thinking were to pervade, it would open the door to all kinds of anatomical dissection, disposal, etc. On the other hand, I know that certain strains of thinking within Christianity and also within Judaism have opposed all manner of post-mortem dissection.

So I think this manner of thinking can change with time, with the prevailing thought. We are raised in a tradition in which you have to show some respect and some reverence. I know that when we are doing an anatomical

dissection, it's almost invariable that the person who is actually doing the dissection covers the face of the cadaver. Even though dust we are and to dust we shall return, and this is no longer a person, still you have the face of the person looking at you, and you have the feeling that it is that person, still is that person.

LAVERA CRAWLEY: What you didn't say and what you spoke to me about in the hallway is how you grew up being exposed to slaughter houses. So the notion of seeing something cut open was not new to you, wouldn't be as shocking, as it would to the medical students who may not have had that situation. As you were just speaking, I was wondering what might happen in future generations of medical students as we move to virtual cadavers, and we get away from the actual human body. What will happen with that?

FRANK GONZALEZ-CRUSSI: I think there is some merit in decreasing the exposure to cadavers. That's my personal opinion. But I know that I'm not alone in this manner of thinking.

The other thing, even more interesting, is what dissection does to medical students. This would probably be the primary concern of an audience like this one. I can see the dilemma that confronts many of you who have to teach humanistic values to medical students. The medical student is exposed about 1% of the time, in a tiny, minuscule portion of the curriculum, to a course that is named "Humanistic Values of Medicine," where the human being is to be explained, not only on the basis of anatomy and physiology but in terms of what that extra thing is that makes a person a human being. So 1% of the time is going to that. And then for the other 99% of the time the body is treated like a machine, the sick body as a machine that is out of order, and there is no reference to this so-called "extra thing" that the human being has.

LAVERA CRAWLEY: Comments on that statement?

JOSE ALANIZ: I'm Jose Alaniz, Comparative Literature, at Berkeley. A lot of things, obviously, keep accumulating with each comment. I was reminded of Thomas Lynch's comment that death ultimately doesn't happen to the dead, death happens to the living. And a lot of the hand-wringing and a lot of these moral

dilemmas that we go through have to do, of course, with our own sensibilities. Respect for the dead body is actually respect for the person who was before, respect for the family or other things, and also for our own sensibilities.

But I wanted mainly to comment on Dr. Gonzalez-Crussi's bringing up Tolstoy's very careful and very intimate reading and very corporeally based depiction of the dying body in *The Death of Ivan Ilyich*. I think it's another illustration, though, of the seduction of the representation of the dead body, how it can be taken in some respects for something that is real. In fact, Tolstoy was using that novel to convince his audience to act in a particular way. Tolstoy uses the dying process, and its power, potency, realness, and undeniability, for political or ideological gain. In fact, he was trying to get people to change their lives, to live in the correct way.

So the main point, I think, is always to think about the representational practices that themselves are depicted in photographs or films [or novels], and to remember that although we are limited in the extent to which we can represent death, we can use its resistant power of representation for other purposes. In that respect, as Sarah Godwin and Elizabeth Bronfen in their work mention, every representation of death is by nature a misrepresentation. It's pointing somewhere else ultimately. And I think the case of Tolstoy is an illustration.

FRANK GONZALEZ-CRUSSI: I agree with the general gist of the comment. I think that the respect and reverence that's owed to the dead is certainly of a different nature than the kind that is owed to the living. In the operating theater, a surgeon is often cutting a body while listening to music. It has a soothing effect. Many surgeons prefer a little background music while they are taking on the operation. Music, as we were saying out in the hall, would not be permitted in the room where the cadaver dissection is being done. It would be considered irreverent, suggestive of too much levity.

SANDRA GILBERT: I just want to make one comment about what seems to be emerging from this discussion of the body. Really, it seems as though we're going around in circles about this issue of respect for the body. On the one hand there's a long Western tradition in which the body, as Frank has mentioned, is the most

abject version of the human being, the ultimate abject spectacle. It's helpless, hopeless, existing, but not existing.

But on the other hand, because it incarnates the mystery of death, it also has this extraordinary nobility. And there is a long literary tradition—for example, a poem by Rilke called “Corpse Washing,” a poem by St. Vincent Millay about viewing a body, and a story by D.H. Lawrence called “Odor of Chrysanthemums”—in which a woman looks at her husband's body, in which the body represents utterness, and a nobility, and is in itself completely a mystery.

I also had a question for Patricia. I was so intrigued by your remark that the passage of death and dying has been colonized by the language of choice. I keep going back to that in my mind, and I can't help wondering about that in the context of the debate over physician-assisted suicide and the bioethic story that was told by Jodi Halpern.

PATRICIA BENNER: I have a sense that part of that has to do with a technological self-understanding and a sort of technical view of death, so that if we choose it and own it, it isn't “other.” And yet it confronts us with something that is radically other, in that there is a way in which we can't choose it. I'm reminded of a story where a patient had had a heart transplant and was now in the throes of rejection and fulminating multi-system failure. Most nurses could not stand to go into the room. The physicians were very distressed and wanted to discontinue all therapies—the futility discussion. But the wife and husband had had a pact that they would fight together, and that she would fight for him, and that they would fight until the very end. Things had become horrible; he no longer looked like himself, it was “ugly” in the way we talked about yesterday. And so they sent a less experienced nurse in to take care of this patient because the experienced nurses just couldn't stand the travesty of it. And this nurse went in because she was only two years into the practice, and she had known this man and his wife throughout his illness.

All day long the physicians were talking in clinical discourse to this wife about the ejection fraction, the multi-system failure, etc., etc. And this nurse is taking care of the man, and she is feeling very sad, and she says, “I don't want to remember him like this.” And she starts reminiscing about his sense of humor and

about the different things that happened on the unit. Well, reminiscing is a kind of leave-taking ritual. And so she goes on, “Tell me about how you met, and tell me about your life together.” And this reminiscing continues. And the woman then says, “If I turn off the drips, how long will he live?” And the nurse responds, “Well, I think no more than a few minutes.”

The wife then walked out of the room, came back in five minutes or so, and said, “Turn off the drips, but don’t stop the ventilator.”

For me, that story is an example of the way choice language doesn’t really capture the issues of letting go, and also that we can do everything and death will still occur. There is a way in which we imagine that death is not quite natural.

JOHN GILLIS: There’s a term here that I guess maybe I haven’t been attentive to in the literature, but this concept of “intimate strangers” really intrigues me. Is that something relatively new in the literature?

PATRICIA BENNER: It’s been around, and it’s also been talked about as a kind of pathology, that maybe you are intimate with strangers but you don’t have a life. So, I mean, that is one kind of pathology. But you can turn it around and look at people with very robust, lovely lives, but who have this capacity to experience solidarity and make connections. I think it’s part of the social tradition of the compassionate stranger that you be compassionate not only to those in your family but to other human beings as well.

JOHN GILLIS: Well, the reason I ask is that—and I think my fellow historians here would confirm this—the presence of strangers was a normal phenomenon up to, really, the late nineteenth century. Sometimes in rather bizarre ways, the deathbed scene would be crowded with people. And then comes along the institutionalization of death, and this circle was narrowed. In fact, what seems to have happened is that one group was privileged over every other: the family, the next of kin. What I’m hearing here opens up a very interesting area of speculation for me, that the next of kin may not always be in the best position to attend the dying person. I think we’ve had several narratives that have suggested this. And I’m beginning to wonder why. It seems that while the next of kin will go on living

their world—that’s your term—the person dying is about to leave that world, and in some sense needs permission to leave that world. The next of kin are likely, in a deathbed situation, to want to sustain the roles and expectations and petty tyrannies that always prevail in family life. This is the curse of intimacy. This is its strength, but it’s also its curse. But the dying person may need permission to assume the role of the slightly deviant, the quirky individual. After all, this is the last moment, and maybe that’s a right that we should all reserve to ourselves at this point. And here, with the intimate stranger, is a wonderful opportunity for that looseness of relations to come into play.

So it seems to me this comes back to detachment and intimacy. It is clear to me that detachment and attachment are vital in these circumstances. But we shouldn’t overplay either of these. It’s important to keep in the situation a certain looseness but also a certain comfort of the known: the unknown and the known.

PATRICIA BENNER: I was thinking of Jim’s description of Fran, the love object. And I could just imagine her, and imagine myself in situations like that, where somehow you’re still able to hold open joking and very concrete particularities, and that you’re really able to meet someone in your common humanity. For the one dying, there’s no risk involved. For the one caring, there’s really no great risk involved. And you can connect on this human level. And I think it’s a wonderful cultural possibility and one that we ought really to hold open and sustain.

LAVERA CRAWLEY: We have time for maybe two more questions.

MICHAEL WITMORE: The terms “detachment” and “intimacy” seem to be defining different sorts of vision. They’re different from other terms like “mind,” “body,” “knowledge,” “understanding.” I’m wondering what difference that particular pair makes. And I’m wondering if you have any sense of whether there’s a term that encompasses both.

PATRICIA BENNER: Detachment and intimacy. That’s a really good question. I’m sure they should not be oppositional, should not be dichotomous. There’s a

way in which if you're just merged and you have no recognition of the other as other, then you can't have intimacy either. So I think we need metaphors like "dance." We're a little impoverished on language for relationship. But I like the notion of putting detachment and intimacy on a continuum and not seeing them as mutually exclusive or in opposition.

LAVERA CRAWLEY: I think we can go on and on here, but time has run out. My thanks to all the panelists and to all of you.

Session Four  
**Speech/Finding the Language**





# Editor's Note

## Session Four

The fourth and final session of *Seeing the Difference* is an open discussion involving all resource speakers and participants. The session is introduced by three Ph.D. candidates who had all participated in a three-day interdisciplinary workshop on illness, death and dying sponsored by the Townsend Center (in collaboration with International and Area Studies) in 1998: Shai Lavi (Jurisprudence and Social Policy, Boalt Hall School of Law, UC Berkeley), Darcy Buerkle (European Studies, Claremont Graduate University), and Elizabeth Dungan (History of Art, UC Berkeley). As rapporteurs of the *Seeing the Difference* program, this group had the important—and challenging—task of summarizing the issues that had arisen in the preceding three sessions and presenting a set of questions and issues to be addressed by the group as a whole. For Shai Lavi, the role of technology in our consciousness of the process of dying is a central issue. Darcy Buerkle, drawing on her own work on a Jewish woman artist who painted her autobiography in the year before she died in Auschwitz, points to the importance of what she calls the “imaginative project” in the face of loss. As the final commentator, Elizabeth Dungan eloquently reminds us of the various notions of vision that have emerged in the two days of discussion, the recurring examples of the spatiality of death, and finally, how both visual and spatial metaphors lend themselves to notions of relationship. —CMG

## Shai Lavi

Ph.D. Candidate, Jurisprudence and Social Policy, Boalt Hall

I got interested in death and dying after I heard from a friend about Dr. Kervorkian. Because I study law and sociology of law, I became interested in the phenomenon of a person walking around basically killing his patients. I thought this was quite extraordinary. And I thought that this whole idea of physician-assisted suicide and the management of dying can't be that contemporary; it can't be that it just started ten or twenty years ago. So I'm trying to trace back the idea where this notion of euthanasia came from, this wish to control the time of dying, of death, and the manner of death and dying. And, of course, I found that it's an ancient idea, but it has a modern history that begins sometime around 1870. There was a notion of the "art of dying" even before euthanasia, but I see the two as related: the old tradition of the art of dying, controlling the manner in which one dies, and the more contemporary notion of euthanasia, controlling the moment of one's death.

What I want to try to bring out from the discussion that we've been having these past two days are some thoughts about time and technology, both of which came up quite often. And they both occur in the photograph that Jim Goldberg offered to us, the image of the watch telling the time of death. The photograph captures both need to have a perception of when death happens, the time of death, and also the technologies that are involved in configuring time.

I think one thing that was raised is this idea that death is universal, that it transcends, in a way, cultural differences. We all die; it's a brutal fact of human existence. But precisely because it is universal, it's also culturally determined: different societies, different cultures have different rituals, different understandings of what death is, and what after-life is. Then, similarly, death varies in space,

and it also varies in time. There's a question of the history or the historicity of death and our understanding of death.

One of the questions that came out of the first panel and to which we return again and again, is what is the precise way in which Americans today, or in the twentieth century, deal and have dealt with death? Are we a death-denying society? Are we obsessed with death? Are these exclusive ways of understanding and dealing with death? And I think that rather than asking whether we are this or that, I think another way of putting the question is to ask in what way these terms help us understand different phenomena concerning dying and how they work together.

There is another aspect of the temporality—not historicity but temporality—of death and dying that I mentioned above as the need to determine with accuracy the time of death. How do we define dying? How do we understand what dying is? We define dying most commonly in terms of time, the last six months left for a person to live. And what does that notion of time do to dying? What is the difference between the existential feeling of dying and the temporality related to it? And how do suffering and pain affect our understanding of time? Time is not only a linear and quantifiable measure, but also something that becomes part of the process of dying.

I've spoken of the medical understanding of time, as well as the human existential experience of time, but also, I think there is a plurality of time that's important. I think that if we look at the different institutions in which people die, we will see a different logic to the way the time works in each. Time in the hospital for the dying patient is different from time in the Hospice. If you have more time to live you're out of the Hospice; if you have less, you're in. What about nursing homes? Or, what does it mean to die at home?

I think it was Dr. Schneiderman who talked about the dangers, or perhaps even the hubris inherent in the attempt to prolong life—even to insist on prolonging life—beyond what seems to be reasonable, beyond what some would call the point where this is still a self. I was wondering whether it is no less hubristic to decide that death has arrived, that, despite the fact that there are some brain signals, some sign of life, to make the decision that this life has come to an end. So I think rather than being faced with the possibility between choosing between technological life or natural death, that we no longer have that option to

go back to a natural death, to think, “Okay, we should stop the machines and allow nature to take its course.” Every decision we make is, in a way, a decision whether to go with the technology or not. Even when we say that we don’t want to prolong life, that we want palliative care, the latter is also a technology of dying. I’m thinking of the morphine drip and the new art of dying, producing a “natural death,” so to speak, by general sedation, and so on.

Finally, there is the issue of emotion and technology. Dr Tripathy talked about the dangers of certainty when the medical profession, even unwittingly, produces notions presented regarding its power to cure or heal or relieve pain. There is also hope, which is no less dangerous, I think, than certainty. It produces the hope that even if there is only a 20% chance, there is at least that 20%. What does this do to the process of dying? There may then be rage when technology fails: the cold rage of the physicians, the heated outrage of the patients, the family. What is the role of technology in that rage?

In summary, our discussions seemed to bring out, then, the schizophrenic condition of a technological age where death has become medicalized, but there remains also the human face of death and dying. We say on the one hand that we want to use technology, but we also still want to enjoy, to recognize the human face, the Buberian “thou” in the dying patient. I think that it is important to see how this schizophrenic condition works, how we live in a split world, in which the human condition co-exists with the technological condition.

I want to end my remarks by saying a few words about another attribute of these two fascinating days of conversation. We usually think of emotions as opposed to a rational discourse of these matters. I was fascinated with the way that emotions and personal experiences played out together in the past two days of discussion. When the subject is death and dying, this seems to be a necessity.

## Darcy Buerkle

Ph.D. Candidate, European Studies, Claremont Graduate University

One of the things that is most interesting to me about these kinds of meetings is that people do come to them for such a variety of different reasons, and some of those reasons begin to get uncovered in a way that doesn't usually happen in an academic context. The dissertation I'm about to finish is called, "Reading the Will: Jewish Women, Subjectivity and Suicide in Germany." It was inspired by the paintings of a woman artist who painted her autobiography while she was in exile in the South of France. That autobiography consists of over a thousand paintings she did in the year before she was killed in Auschwitz. And it is really the story of the way in which she imagined the reasons for her mother's suicide and also her grandmother's suicide. There were a total of six suicides in her family. Hence her project was really an imaginative one, completely preoccupied with the possibility of an explanation of those losses.

Right now I want to speak briefly about two ideas that have come up over the last two days. The first is imagination. It is probably clear from what I have said about my own work that the imagination plays a very pivotal role for the artist I am studying, a woman who spent twenty hours a day while she was in exile creating paintings. Those paintings have trace-paper overlays on them, and the narrative of her life, and of her mother's life, is written on the trace-paper overlays.

It's my feeling in talking to people over the last couple of days that as a group we actually divide up into those people who think the conversation [with the dead] goes on and those people who think that it doesn't. That notion is usually coupled with belief about the possibility or impossibility of a world in the aftermath of loss. And I wonder about doing those things together. Might it be true that a reconstituted world in the aftermath of such a death is a world

constituted of the very vestiges of an intimacy that remains? That is, if there isn't a continued conversation, is it perhaps the case that there is a continued intimacy? And how might we describe that? What would be the phenomenology of that intimacy?

Secondly, I wanted to ask some questions about language, and suggest that we might discuss whether there is a discourse of the dead, a discourse of the dying. And also to add to that, motivated in part by Michael Witmore's comments yesterday, is there a discourse of the near-death, and what authority do we grant or not grant that experience? Are we so committed to the inevitability of death that the near-death experience is necessarily invalidated or ridiculed? I wonder about that.

And I wonder about this too in connection with Shai's comments about time. The near-death experience marks time in a radical way, particularly since time continues to go on. And how do we account for that marking of time? Do we say that we now have a new relationship to our mortality, or do we have a relationship to death for which there must be a language and there must be some description?

## Elizabeth Dungan

Ph.D. Candidate, History of Art, UC Berkeley

Often when I describe my work to people, they say, “Oh, well, you must know a lot about death.” And I am always amazed because that was the one thing that was not imaged through the medical imagery that I was looking at. That was something that might fall out of the medical journals and the articles that I was scrutinizing for visual material. And so that absence allowed me to start thinking about representations of death and the difficulties therein.

In consideration of some of Darcy’s comments and also Shai’s, I want to bring out this theme of vision that has been so dominant in the last two days, and also, of course, the imagination that is linked to the image. I think that vision has a relationship both to the imaginary and to the externally visible. And, obviously, Tina’s titles and subtitles have structured the last two days in relationship to vision and visuality.

I’ve been struck by the number of ways that vision has come up as a metaphor for all the explicit topics. In one way, of course, these two days have been catalyzed by Jim’s very first line, saying that he “could feel something, but he couldn’t see it,” and he was trying to work in the gap between the two. And the captions that appeared on the many images that he showed us often figured people who were offering themselves in relation to the eye, to the eye as an organ, but also to subjectivity. So, for instance, some of the captions were, “No one knows me, I’m an invisible person,” “I look pretty good, except that I’m bald-headed,” or “I used to be handsome,” or “I used to be beautiful, and I’d like to see a picture of you when you’re seventy-six years old.” So all of those images were also structures of self, and they all were in relationship to the eye and visibility.

I was also really moved by the sights and visions that Sandra was alerting us to in the whole relationship to the loss of a loved one, the attraction, the seduction. She described the experience as a kind of mirroring process, a kind of mimetic relationship that is a kind of visibility. I think explicitly of the double sight that All Souls' Day brought about. That double sight came up over and over again. Shai talked about it in reference to schizophrenia. But we've all been talking about double sight: for instance, Michael's description of the early modern prescription for double sight with one eye to God. And I think Gary also raised that return to sight, this doubling-up of the sight, when he talked about embalming and the whole idea of re-presenting the body and allowing it to take a form that is visible to us, and emphasizing that last look, that that is a means of connecting. And while it might be an idealized representation, Gary brought up the problematics of that, of a presentation that is an address to the eye.

And, of course, Jodi brought all of those words together with her discussion of recognition as a means of a potentially empathic relationship or a sympathetic relationship. In Jodi's terms, "recognition" is established through a self/other dichotomy that finds connections and interdependence through the sense of sight, through this facing-off between the self and the other.

But with all of these meditations on sight, I think we were all talking, too, about the kind of interruptions of that sight, the distortions, the deferrals of sight, the vagaries or the ambivalence of sight. And that came up even when we were talking about the case of moving all the peripheral things out of the room of the dying, in order to allow our look, our gaze, to be more focused or central. Or to go back to the very icon of this conference, Jim's photograph, we see that time has an apparent clarity, but the person, the father, the body—that figure in the background could stand for many things—is out of focus.

So all of those different kinds of visions, those different kinds of visual experience, say something about the position of the viewer.

And that leads me very briefly to the second theme I wanted to alert us to, and that is the spatiality of death. There is a notion of location that we have been talking about throughout the last two days. Of course, the opening of the door has been central to that, this moving into the space, or allowing death to be a spatial thing that opens out through us. And then, just recently, Patricia Benner

was talking about holding open that world, holding open a spatialized sense of the world.

Spatializing death implies as well a kind of access, a kind of movement. And Gary, of course, pointed this out when he was talking about the importance of location in death, talking about the various experiences that shift depending on the location of death, whether it is on the fields of war, or at home, or within an institution.

In the notion of double sight, again, Sandra raised the idea of the doubleness of location: that Elliot could be there in “this pale shiny hospital cubicle,” that was the space in which he was both living and dying in those six hours. Sandra reminded us of the concomitance of being both near and far, of looking upon someone who is dying and is interiorally and physically, presently, there, nearby, but is also one who is moving far away.

Finally, the reason that I’m bringing that notion of spatiality up after visuality, but in relation to visuality, is that both of those themes conjure up notions of relation, a kind of relational ethics that we end the conversation with. I want to emphasize that it is not only the very situated knowledge, or positionality, that Dr. Crussi was talking about that is important. How we navigate, how we work relationally, are also crucial; and sight—the process of looking—and physical location are integral to this work.

**Session Four:**  
**Speech/Finding the Language**  
**Discussion**

CHRISTINA GILLIS: I expect that people will think about these questions in relation to their own experience, and these questions will have different answers according to who you are or where you are, and the sorts of issues that you face. Who would like to begin?

FRANK GONZALEZ-CRUSSI: I want to answer one of the questions in my capacity as head of a department of pathology. Just to be controversial, I will posit that science and technology, which speak so loudly about having enhanced life and prolonged our lives, have done more to diminish than to enhance. If you think about how the primitive mind functioned before, I think that a logical conclusion is really that one could see the whole universe as primarily alive, you know. You look at the clouds: the clouds are changing shape, and flying in the sky, a bird, you know. Look at the trees in a forest: they are growing and they live, they are alive. Everything is alive.

Now comes science and technology, and they teach you the opposite. They say the clouds are vapor, the winds are a physical phenomenon, the stones are made of inorganic material. You, too, are made of inorganic material. The only difference is that, you know, by a strange combination of micro molecules, you get to come alive. But, actually, the scientific position that I've read in this context clearly says that life is an improbable phenomenon. When you consider that it is the equivalent of all these micro molecules, the enzymes and the energy that needs to be put into the system, life is a very improbable phenomenon.

We are really an exception in a universe that's mostly death.

Science and technology often create a gulf between our present and existential experience and the phenomenon that we confront. If a surgeon tells me I have an 80% or 20% chance of getting this complication, or suffering this disease or whatever, this will never help me plan anything. It's either I get it or I don't get it. If I get it, it's 100%, if I don't get it it's 0%. So there is always a gulf or a distance between the pronouncements of science and technology and the human vantage point in which we are placed.

SANDRA GILBERT: I think everything you said is completely right. But it leads me to want to ask the questions that I have been talking about with several people over lunch, and that is, why have we completely ignored issues having to do with religion? After all, death is arguably the reason we have religion. I mean, religion exists because of death. And at the same time, religion constructs death in different ways cross-culturally.

I don't know what to do with that. As a group, probably most of us in some part of ourselves subscribe to what we have learned from technology. Yet at the same time, archaic parts of us subscribe also to various kinds of religious views that we haven't discussed at all here. And, in addition, we are a very, very small minority in a culture in which, as I read in a recent issue of *The New York Times Magazine*, something like 84% of Americans believe in an afterlife. And the ways in which we confront and experience death are surely inflected by either the belief in an afterlife or the disbelief in an afterlife, or by what I would say is probably my own view, which is some form of Pascal's Wager. And I'm sure most of you know what Pascal's Wager is: to live as though there might be an afterlife because what can you lose if there isn't; and if there is one, you're doing the right thing.

PARTICIPANT: That was a beautiful speech, by the way. Kind of a damning one, but a beautiful one. It seems that the role of religion is always very ambiguous to me, and a few examples come readily to mind. Jim's photograph of the watch, the clock, showing the hour of his father's death—indeed, the minute and probably the second—disturbed me because it seemed like there was an artificiality to it, that the process of death, as Beth was saying, has an extent in space and time, but this watch seems to be pinpointing it, or trying to. And it reminded me of Guy's discussion yesterday about the monitor that keeps beating and beating, when the

person is perhaps for all social or familial, or practical, or emotional purposes dead, but because of this detectable electricity that technology enables us to represent, a body is said to be alive in some artificial, synthetic way. So that's a negative side of technology. But on the other hand, the apparatus that Jim used to make those amazing photographs is another example of technology, the apparatus that's recording what we're saying and so forth is yet another example.

Incidentally, I want to say, too, that if we are a tiny improbability of life on the outer parts of this speck of dust in the universe, that's a dark and lonely vision; but in some sense, I think, it also accentuates the wonderment of life, too.

MONICA WARLAND: I'm Monica Warland. I'm studying Organizational Psychology at the University of Michigan. I wanted to add something that I've been thinking about and ruminating about over two days, and that is that science and technology have made social wholes and groups and social relationships devoid of life as well. So we become atomized and individual, and don't acknowledge the power and the life that exists in social gatherings, and groups, and in individual interactions and relationships. And one thing that was remarkable to me this morning was that the life of connection was so readily juxtaposed with that scientific, philosophical view of remove and individuality.

One of my projects has been to try from a psychological point of view to reconceive what emotion might be as a social and relational thing, rather than as an individual thing. If emotions are of the social whole and they allow us to connect with the life of social entities, individualizing those emotions is another way of stripping that life away as well.

PARTICIPANT: I wanted to say something that addresses the issue of religion, but from a position of belief and unbelief, perhaps, at the same time. I want to respond to something that Darcy said about suicide because the subject has come up but then has gone down again. There was a suicide in my life; my stepfather killed himself when I was eighteen. And I do think that when you're close to someone who commits suicide, you feel the conversation is broken off. And what that left me with was a feeling of tremendous guilt because I hadn't liked him. In fact, I had at one point in time actively hated him. So when he died, it did feel to me as though my wish had been enacted.

Now, fast-forward many years, I found myself in a church, which for me was an unusual place to be. I went in on a kind of tour of the church, and then I sat down for awhile afterwards. And I found myself in a kind of meditation about my life and the significant events in it, and that was one of them. And as I was sitting there I started to cry. Over time, as I sat there crying, because I didn't want to get up and walk out that way, I started talking to my stepfather in my imagination. I wasn't talking out loud, but I was in some way addressing him as "you." And I found myself saying, "I am sorry. I'm sorry that I didn't like you, didn't know how to like you when you were alive." And I began remembering things he had done for me that I really appreciated. So I spent a long time in this conversation with this dead person, this long-dead person. It wasn't as though I truly believed he could hear me, but it was also as if I did believe he could hear me. In some way, it was important to me to do this as a direct address, rather than analyzing my own feelings in a kind of third-person way.

So I'm wondering what it was about having what was, in my mind, a conversation with someone I knew to be dead and didn't actively believe could hear me, but on some level thought might be a kind of ghost presence who could receive this message that made a difference to me? Sometime after that, I found myself doing the same thing with my father, who had died when I was nine years old. It was not a suicide, but he died in a very sudden way, which had the same effect of breaking off the conversation. And then I thought, "Am I crazy? You know, is this a crazy thing to do?" This doesn't feel like me on one level, and on another level it really does. These conversations make a difference for me. I don't know that they make a difference for my father and my stepfather, but they certainly make a difference for me. And they changed my relation to the past, my memories of the past, what the meanings of my own history have for me. And those changes affect the way I'm behaving in the present.

PARTICIPANT: There's this notion that the dead are in some kind of different state. I mean, they still are able to come back after having gone to the other side.

And the same thing with near-death experiences, which has come up briefly a couple of times. There's an interesting book that's been out a while now, by Carol Zillesky, called *Other World Journeys*, and she looks at contemporary near-death experiences and medieval experiences of Christians who have an experience

of death and come back to life. So she frames it in terms of religion, with this interesting concept of the religious imagination, in terms of trying not to explain these experiences, but to understand and interpret them and give them meaning. It's a very practical, theoretical perspective; it's pragmatic. And in a similar way, you were just talking about your own experience. In looking at near-death experiences, you can't explain them away and reduce them to physiological kinds of changes, and you can't necessarily take them literally as the truth about what happened. But there's this kind of middle ground in interpreting them and trying to make sense of them that relies on religion as an important kind of language, a very imaginative language, not like it's all fantasy, but that it has practical value in the life of the person who has had the near-death experience. It's life-changing, and she ties it to other kinds of Christian pilgrimage journeys, like conversion. She looks at the ways in which modern near-death experience has become a kind of narrative of conversion, even though the key part of the story is "My life changed."

SANDRA GILBERT: There's an amazing book. It was published sometime in the early 60s, I believe, or maybe the 70s. It's called *The Vestibule*. It's a little paperback, and it's about near-death experiences. And one of them was a story that was recounted by a couple of doctors in the *Canadian Journal of Medicine*, or whatever. And these are two cardiologists, who are recording a near-death experience of a guy whose heart stopped—it's the usual story, we'll recognize it now because it's a cultural trope, like an urban myth or something, you know, the tunnel, the light, the floating. Well, you laugh, but, I mean, it's a very important, interesting phenomenon, and I don't know what to make of it. But, anyway, they say they felt it was very urgent to publish this in a medical journal because it would help other cardiologists to help people die, and to have people feel confidence and trust, and to help feel that dying was easy, dying was wonderful.

Eddie Richenbacher, who had a near-death experience, who talks about how, you know, "...it's just so easy to die, it's so great. I had to fight to come back." I mean, again, you recognize the rhetoric.

And we haven't talked about that at all. I mean, it's a completely different take on dying. It fits in with the spiritualist movement that we were also talking about at lunch. I don't know where to put it in terms of the conversation we've been having here, but I wanted to bring it up.

PARTICIPANT: Having had what may be a representative near-death experience—I'm not sure I want to say that that's what it was—I have two reactions to it. One reaction is that it's reassuring to know that it *didn't* happen, and that's had consequences and has helped me think about it. It is also consequential that it might have happened. And that makes me think that there's something about the hypothetical power of death, which remains present, whether that's the hypothetical presence of someone—who is dead—whom we don't know is still alive, but we have to talk to anyway, or that case, “suppose if,” in which you would be the one who died. Both of those forms of imagining seem very powerful to me.

Having been raised an Evangelical Protestant and then having lapsed from the Church, it is almost irresistible to me to say, “This [near-death experience] was meaningful and is clearly a turning point in my life.” That particular story and form of that story is so available to me because of the religious tradition that I was raised in. The vocabulary comes from that tradition, the plot comes from that tradition, and I've rehearsed that plot in the work that I do on Protestants in the early seventeenth century.

So I want to acknowledge that religion may be the only vocabulary that many people have, certainly, one of the vocabularies that I have. But the experience of the conference has led me to believe that there are other vocabularies that share some of the qualities of philosophical reflection, but also are intuitive, affective, and I'm reluctant to say spiritual, or at least gesture in that direction.

PARTICIPANT: My interest and my primary focus of caring for children who are dying and grieving children. And children, if they have the opportunity to be natural, often have conversations with those who have died. It's when the adults around them think that's a little strange that they stop having these conversations.

That leads me to your comment. I haven't thought about it before, but when I first looked at the questions we have been given about what voices are given authority in discourses about death, it occurred to me that one group of voices that is not given any authority at all is children's voices. And I can't help but think after hearing this discussion that in today's world it's primarily the scientific and the rational that's given credence. Those are the voices we listen to. And maybe that's the reason we don't listen to the voices of children, because they really are very unscientific

PARTICIPANT: I want to add that the Hindu tradition describes the five functions of the divine as being creation, maintenance, destruction, concealment—meaning our own sense that we are only our limited person—and then grace, meaning revelation that we actually are more than this limited ego or body. And I've been exploring that idea or playing with that in my own belief system. I believe in that moment of grace, that there is a conversation that can happen with people who have died. As a bereavement counselor, I really encourage people to have that conversation, that it's not crazy, it's actually very therapeutic to have that forgiveness experience, and that connection, and that reaffirmation of the love, and to feel the relationship move to a different level.

PARTICIPANT: I wanted to look more at the idea of passage of time, and note that in our society there's a certain amount of time during which it's okay to be grieving or going through some sort of ritual process. But, in fact, if we take that aspect of grieving as a liminal state in the process of separation or transitions, and if we look at liminality as part of that transitional period that people go through when they've lost somebody, then it means that the period can be any length of time at all. In fact, it really doesn't matter how long we're dealing with it.

I also wanted to bring up that in archaeology, the thing that we find incredibly difficult, in fact impossible to recreate, is time. How long it took, for example, the body to be prepared for burial, and what sort of ritual, how long that ritual took. We might presume several days in the way that we see it. It might have taken months, it might have taken years. There might have been secondary burial involved. I want to emphasize how differently time can be perceived.

CHRISTINA GILLIS: At the end of the day yesterday, Gary and several other people mentioned that maybe we weren't paying enough attention to other traditions that give us other vocabularies and lenses for looking at these issues.

GARY LADERMAN: Well, I think that's changing. I just received something from a medical institution in San Francisco. It's a handbook, a kind of multicultural, multi-religious handbook on how different religious communities understand death and dying. It's published for hospitals. So I'm wondering whether within medical communities, not just in San Francisco but maybe even in Mississippi, there's a

kind of sea change where, just as in so many other areas of society, there's a kind of interesting pluralism, religious pluralism coming into play as an educational tool.

PARTICIPANT: I'm a post-doc here at Berkeley. And I am thinking a little bit more about this issue of time that Christine brought up. I did research in Hospice settings, and in these settings I've talked to a couple people about the representation of death—how it's brought into language, what it looks like—and I think its temporal structuring is central. The Hospice setting isn't a space of sudden death, but of anticipated death, and it's about, primarily, the experience of waiting and the shaping of that experience.

So I find myself thinking about how Hospice is a kind of critique of modern death ways, of certain notions of progress and technique. The paradigmatic gesture of draping a blanket or holding hands, or whatever, kind of reenacts an imagined time in the past when dying was different or better. And at the same time, for patients, dying is in large part a movement back into the past, this unlearning of basic bodily functions.

Sandra Gilbert mentioned the embarrassment or difficulty of talking about some of the issues around death, even in these sympathetic settings. And I was trying to think to myself last night, why would that be? And it seems to be that it's untimely talk. For the one who is grieving the past is interfering in the present in a very significant way, and, for others who aren't affected by that, the introduction of this kind of interruption into our linear sense of time is unsettling. It perhaps forces us, or makes us acknowledge, something that normally we don't have to.

The final thing I would say is that for me the breakdown in the conference is maybe less between clinical talk versus human passage talk, caregivers versus patients. In Hospice settings it always seemed to me that there were two endings that were being conceived of. For patients, it is the end of the life or end of a certain experience in time, and for caregivers it is often the ending of the body and the possibilities for reaching beyond that.

JOHN GILLIS: I just want to throw out something that arises out of one of Sandra's first remarks, and that is to get back to this question of what people in this society actually believe, and how most of the people in America find our conversation today a little out of whack, not perhaps totally repugnant, but it's

this question of afterlife. Most Americans believe that people don't actually die, but rather are living somewhere else. It's not a place that is accessible to us physically. But they are living remarkable lives, remarkably like those which they've left behind. Which poses, I think, a most interesting sort of thought question. Why can't we imagine dead people being truly dead? To do that one needs only to go back, I think, about a hundred years in Christian-Judaic thought, where the dead really weren't alive, but existed in a kind of spectral state, or they existed as souls, and so on.

One of the things that I think really poses a terrific problem for modern society is our lack of imagination about the state of the dead. We seem to be incapable of imagining any other life except our own. This is a completely ego-centered discourse that is beyond this room. Of course, we're all exempt, you know, we are acute, we are insightful, we are etc. But there is a larger cultural problem, I think, out there, that I just put it on the table to be aware of.

GARY LADERMAN: I want to echo those sentiments and step back and think about how we use the notion of "we," or how we think, and try to generalize that. There's someone in philosophy at Emory, who is working on religion and science, and he looks at the cognitive angles, at the relationship between religion and science. He's going to come out with a book that basically talks about how, in terms of how we're wired. We're more wired to think religiously than to think scientifically. It's more natural in human cognition to think in terms of religion than to think about science or to think scientifically about reality.

So I think your controversial statement is provocative, but I think it's not how people think. People don't think that it's unknowable. It depends on what criterion you use to talk about how you know, and how to separate out what's just a claim of knowledge and what we know as fact. I think people generally tend to think more religiously about that. It's not the end; it is continuation. It is a passage.

A great book was written a few years ago called *Heaven, A History*. The author looks at the way the history of heaven changes in Western tradition, and how in the contemporary period, it's become very domesticated. Especially in the twentieth century, the kind of theologies of heaven disappear, and they're not as forceful or as out there, as strong as they were one hundred years ago, or two

centuries ago. Like some other people here, I'm very hesitant to bring up spirituality; I don't feel comfortable talking about spirituality as a descriptive term of American religious life, but spirituality kind of fills the gap. And so we have films like *Ghost*, we have these notions of individual spirits that can penetrate the veil and come back into this life and affect us. And we've lost the kind of theological structures—and believe me, I'm not saying that we need them or that we should go back to them or that I'm nostalgic for them—but in our society, they've been lost, so in a way anything goes in terms of how we imagine the dead.

PARTICIPANT: I think Charles Taylor makes a really strong claim that our spiritualism has moved into science. Our spiritual imagination is one of freedom and liberation through disengaged reasoning and through standing over against the world in this particularly scientific way. In this view, what appears to be very irreligious is spirit-filled and a spiritual quest for freedom and for liberation.

GARY LADERMAN: I'm interested in this medical model, the medicalization of death. Implicit in that is the secularization thesis, and religion is no longer a part of that. I'm wondering for people who are in the medical setting, does religion make an appearance? I mean, how does religion come back? I think medical professionals can't talk about this stuff with each other. I think probably it's more comfortable when you're in this kind of setting with people in the humanities, who are accustomed to hearing a lot personal opinion, personal experiences. But as far as I know, what little I know, that can't be part of the medical discourse. It would undercut the scientific, explanatory, reductionistic models that are so essential.

PARTICIPANT: Personally, I find that I have to be very careful with whom I share certain things. Some nurses and physicians, yes; others, definitely not. We've just written a paper on spirituality and pediatric palliative care, with the idea being that spirituality is an element of what Patricia was calling earlier "relationship." It's part of getting to know people and finding out what's important to them, so that you can help them with what they need at that particular time. So I think much of what you say fits with my experience.

SHAI LAVI: On the same topic. I'm very skeptical about the possibilities that we have to die different deaths. I think that we're struggling here to come up with alternatives in the name of religion, in the name of spirituality, in the name of the Hospice, in the name of some personal experiences. But it's not clear to me that these are really options that are available. Not that the only possible death is death in the hospital, but that death in the hospital, the medicalized death, can really affect in a profound way, a very strong way, the other alternatives of dying.

The Hospice is not an alternative to the hospital. The Hospice and the hospital belong together in the way we die. Right? The Hospice will accept you only if you have six months to live. What does that mean? Who determines that? This is a medical determination. The Hospice offers no medical technologies for coping with death, but it offers us five stages in the process we need to go through when we die. And it's not that it doesn't have spirituality in it, but it's really a kind of universalized spirituality.

I'm wondering whether, instead of trying to fight technology and science in looking for an alternative, we need to have a better understanding and a deeper understanding of what technology and medicine allow, and see that they're not limited to the body as opposed to the spirit, they're not limited to rationality as opposed to emotionality. But rather, then, we need to look at what kinds of emotionality are involved in technology, what kind of spirituality is inherent to technology. That doesn't mean that we shouldn't try to imagine other possibilities, it's just that we should come to terms more with the fact that we don't have them present at the moment.

GUY MICCO: The first thing that occurs to me, Shai, is that what's behind our medical technology is the desire to bring immortality. We want to live forever, and that's what keeps driving the technological imperative, to continue life. There's some people who say they don't want to live forever. I personally have doubts about that. I think we want to continue a good life, barring disability and strange things happening to little gray cells. We want to continue at whatever age we felt good at. I feel good right now; I'd like to continue like this for a really long time. Technology has that pseudo-promise that someday stem cells will make it possible.

SHAI LAVI: I think technology isn't about prolonging life forever; technology is about determining the manner and time in which we die. So it could be the prolongation of life forever, but it could also be physician-assisted suicide, terminal sedation, and other ways of accepting our death. Technology is really about having more control over death.

GUY MICCO: I agree. Right now, technology is about control. As I said, yesterday, a large study in San Francisco, in the Intensive Care Units at UC San Francisco and San Francisco General Hospital, showed that 90% of deaths were preceded by a decision. So there's a decision to stop the technology that is prolonging life.

But I wanted to skip over to this question of spirituality and medicine, which I find, and many physicians find, strange bedfellows. Yet it's coming. Spiritual history will be part of medical history in the not-too-distant future, if it isn't already in your medical school right now. And it's doing more than just asking what religion are you, it's actually looking into meaning, life's meaning, and the meaning of spirituality to the patient, and considering that with the patient. So medical students are starting to learn those things. And it's an uneasy alliance. I think people feel a little bit uncomfortable; physicians feel somewhat uncomfortable. Just as physicians feel uncomfortable with this notion of the near-death experience that we have been discussing this afternoon. Medicine did with the near-death experience what it does well with other things. It studied it. I only know of one study; it's in the *American Cardiology Journal*, the last time I looked, which was a few years ago. In that study, many people were asked after they were resuscitated what their experience was. And, not surprisingly, the experience was no experience, zero, nothing, no memory, nothing. No light. So that was medicine's dismissal. That's all I've ever seen. Dr. Gonzalez-Crussi discussed in his book wonderful stories about feeling good at the end of life. But as far as near-death experiences with tunnels of light and whatnot, that's not the experience that's been reported in the medical literature. And the rest, I'm afraid, is merely anecdotal.

GWEN ANDERSON: I'd like to bring up something else, and that is the whole aging population around the world which is going to continue to grow. And the

whole idea of a technological fix to aging is still a long way off, and yet at the same time we've got technology that is impacting aging, such as, we have people who have gone through a whole generation of chemotherapy, and now they're living with chronic conditions, for example. They are people who are experiencing some degree of social death, in a way, because their life is limited. So they are not necessarily fully living a life, nor are they dead, and nor are they necessarily in the process of dying. But the way of living that they had has changed. So I wanted us to think a little bit more about how we are going to accommodate all of these processes of dying, or these preparations of dying which are not necessarily included in the language of a total death.

I raise this because for a number of years I have lived with one elderly person who has now died and now I'm living with a new elderly person. And I think one of the responsibilities we have, because we are so attuned to living and dying and death, is to bring the new generation that's coming up behind us into our conversations about dying, to help them realize that they also have a responsibility. For instance, I feel a responsibility to help elderly people with their dying. My notion of what dying is has really changed as a result of living with these people. For instance, with one individual, who went through two strokes and was diagnosed with Alzheimer's, his dying probably started at least eight months before he actually died. I was there and living with that, and coordinating really extensive services coming into the house. Now I'm working with this new person who lives on a twenty-six-foot cord of oxygen, and I have to beware of something as simple as the house-cleaning person plugging into the wrong cord, and all of a sudden the power is gone and there's no oxygen. The oxygen is this person's lifeline, and she could die in a matter of minutes without it.

I would like us to think as we leave here about really creative ways of accommodating these changes. If we've got more and more people in society who are getting older and who are living with chronic illness, how are we going to help them?

ERNEST LANDAUER: Entailed by this comment and by all of the other comments, centering, focusing on the question of what voices are given authority in the discourse of death, I note that we've been using the passive voice. So there's a question: Who gives the authority and what is the authority? Authoritativeness is

being informed; authority is having power. And the two may not go together very often; we often are led by leaders who are very lacking in authoritativeness, while having a monopoly on authority. And that happens in our personal lives as well.

There was a comment earlier by the participant behind me about social relations. I think many things that we attribute to each other are really the product of relations and the ongoing interpretations of those relations. Dr. Benner used the phrase “common humanity.” It’s the only time that there was a mention of common humanity. And that, in a way—whether we think of it transcendently or locally—that is what gives us authority, and we can at a given moment consensually validate that by checking it out with whomever we happen to be with. I won’t go into a long personal reference, but I’ve had several experiences spending a long time with older people, who practically to a person always say at some point, “Why does everything take so long?” That is, there is no implication there of immortality or with the desire for immortality. There is, however, a desire for continuity, and that is the identity we have with old people, middle-aged people, young people with whom we have a common humanity, which includes all those things that we think of as inhuman. That is, it is only human beings who can be inhuman.

DEBORAH BARRETT: I’m Deborah Barrett, and I’m an independent artist. Much of my work has to do with the dead, or with death, in the sense that I use mid- to late-nineteenth century portraits as references for drawings that I do. So, in fact, in some ways, I’m really relieved and gladdened to be in a group that has concern with issues of death. Because as I do these drawings, they really are kind of a meditation on life and death.

I wanted to make a couple of observations. You know, I am of such an age that I actually remember funeral processions. And I get kind of cranky about what’s happening to this culture, in the sense of denial. I really do believe that this culture is becoming something of a Disney park. I am often reminded of the scene in Pinocchio where the children are lured into this Coney Island-type environment. I think that we live in a similar environment as it pertains to death. When was the last time any of us saw a funeral procession? I remember when I was growing up that the rule was—I thought it was a law—that you never went in front of a funeral procession. So if it were a two-lane highway, the whole fleet of

cars behind this funeral procession would, in fact, become part of the funeral procession. When was the last time you passed by a cemetery? One of the things I love about going into New York City is that if you look very closely and if you take the Carey Bus instead of a cab, you're up very high and you get to see the enormity of the cemetery. It goes on and on and on and on and on.

I think that we lack these cues, these visual reminders that we're just passing through. The whole talk about technology and the notion of prolonging life or suspending death is part of the aversion to death.

Four years ago, my stepson died suddenly, and he was twenty-three years old. The suddenness with which that happened, it was physically as if I had been smashed in the chest. And what that force was, was the realization that, in fact, death is that close, death is a phone call away, death is a step off the curb, you know, death is six inches on a highway; it's here, it's all around us.

My brother died in January, and his death, too, was unexpected, although it was not quite so sudden. He was taken off a ventilator. I was very grateful for what you had to say yesterday, about what happens to the body because I wasn't given any information, nor was my other brother given any information as to what would happen to him, except that he would die, and he was supposed to die within an hour. And, in fact, he lived for a week. What I realized—and we were talking about this at the break with some other people—was that I had been waiting for this. And I realized I was participating, and could be a participant in this. I bought two books of poetry, one by Rumi and another by Mary Oliver. And I had been talking with my brother earlier that week, going back over our life together and when we were children together. But the realization mid-week was that I was like this midwife; I was a coach. And it allowed it not to be death; it allowed it to be this thing that I was going through with my brother, that he needed me there. He wasn't conscious; he couldn't respond. I read him the poetry; I talked about fishing, how he loved to fish as a child. And he didn't die until the following Saturday.

I felt the day that he died that we had done very good work together. You know, I felt that it was a labor. And when I walked out of that hospital, after spending time with him, after he had died, and my other brother joined, and we spent time with him together, my whole notion of death was this big thing. In some ways the talk today, or over the last couple of days, is of the enormity of

death, that it's other. And I don't think until we really experience it from whatever point of view, only then does it become part of us.

The real tragedy is that we go out into a culture and it's not reflected back; it's not made real for us, so that we're isolated and alone with it until the time that it happens, whether it happens suddenly, or over an extended period of time. This is one of the reasons that I love going to Mexico, where it is part of life. And traveling through small villages and seeing funeral processions—I know that sounds really trivial, but it makes one feel not quite so crazy, and that death is not a failure. Whatever it is for anybody, whether you're spiritual or not spiritual, or religious or a scientist, you know that death is a mystery, but it's not a failure.

And finally I just want to say that I am grateful to have been here—to all of you. It has been a rich, rich experience.

CHRISTINA GILLIS: I think my own response to that is that my own first image for thinking about the conference, about a year ago, was the photograph in the *New York Times* at the time of the Nova Scotia plane crash at a place called Peggy's Cove. John and I lost a child in a plane crash, and we're very sensitive to happenings like this. In the image in the *Times*, which was on the front page, we saw a rocky shore with the sea beyond. But it's all rather misty, and it's hard to see anything there. This photograph seems to be about what is not known. Officials are apparently still looking for the black box, which will presumably tell us why this plane went down. The image shows people whom we assume to be the family of the crash victims—we don't really know of course; maybe they are only visiting there, tourists, but the story tells us that family members are gathering in the hotel in Halifax. We are also told that everyone is waiting for the message of that black box, and they are waiting for body parts, and they are waiting for news. I have a hard time even getting my imagination around that particular thing. But certainly, the image was important to me for what it says about the human condition, and the relationship between the living and the dead, the known and the unknown.

Finally, I would like to thank all of you for coming, and particularly, those speakers and participants who came long distances to be here. Do come back and see us, all of you.



## Appendix One

# Conference Program

### **Thursday, June 1, 2000: Morning Session, 9:15–12:30**

#### I. Silence, Art and Ritual

Chair: Christina M. Gillis, Ph.D., Associate Director,  
Townsend Center for the Humanities  
Jim Goldberg, photographer, San Francisco  
Sandra Gilbert, Ph.D., English, University of California, Davis  
Gary Laderman, Ph.D., Religion, Emory University  
Commentator: Jodi Halpern, M.D., Ph.D., Joint Medical  
Program, University of California, Berkeley/San Francisco

### **Thursday, June 1, 2000: Afternoon Session, 1:30–5:00**

#### II. Time—Counting the Moments/Making Moments Count

Chair: Gayle Greene, Ph.D., Literature and Women's Studies,  
Scripps College  
Debu Tripathy, M.D., oncologist, UCSF  
Michael Witmore, Ph.D., English, Carnegie Mellon  
Lawrence Schneiderman, M.D., bioethicist, UCSD  
Commentator: Guy Micco, M.D., Joint Medical program,  
UCB/UCSF

**Friday, June 2, 2000: Morning Session, 9:15–12:30**

III. Vision—Confronting the Margin

Chair: LaVera Crawley, M.D., Stanford Center for Biomedical Ethics  
Thomas Cole, Ph.D., historian, Institute for Medical Humanities,  
University of Texas Medical Branch, Galveston  
Frank Gonzalez-Crussi, M.D., pathologist, Children’s Memorial  
Hospital, Chicago  
Commentator: Patricia Benner, R.N., Ph.D., physiological nursing,  
UCSF

**Friday, June 2, 2000: Afternoon Session, 1:30–4:00**

IV. Speech/Finding the Language

Presentation of questions and issues raised by sessions I–III

Darcy Buerkle, History, Claremont Graduate University  
Elizabeth Dungan, History of Art, UC Berkeley  
Shai Lavi, Jurisprudence and Social Policy, Boalt Hall School of Law,  
UC Berkeley

## Appendix Two

# Conference Participants

Jose Alaniz, Doctoral Candidate, Comparative Literature, UC Berkeley  
Gwen Anderson, R.N., Ph.D., Post-Doctoral Fellow, Stanford Center  
for Biomedical Ethics

Anthony Beck, Ph.D., Division of Medical Oncology, University of  
Washington

Deborah Barrett, Artist

Patricia Benner, R.N., Ph.D., Professor of Nursing, UCSF

Darcy Buerkle, Doctoral Candidate, History, Claremont Graduate  
University

Gail Bigelow, Coordinator, Bereavement Program of the VNA and  
Hospice of Northern California

Pat Branch, Townsend Center for the Humanities, UCB

Gretchen Case, Dramatic Art and Dance, UCB

Carol Christ, Ph.D., Executive Vice Chancellor and Provost, UCB

Thomas Cole, Ph.D., historian, Institute for Medical Humanities,  
University of Texas Medical Branch, Galveston

Mary Coombs, School of Social Welfare, UCB

LaVera Crawley, M.D., Stanford Center for Biomedical Ethics

Elizabeth Davies, Ph.D., Family Health Care Nursing, UCSF

Elizabeth Dungan, Doctoral Candidate, History of Art, UCB

Christine Finn, Ph.D., Institute of Archaeology, Oxford University

Sandra Gilbert, Ph.D., Dept. of English, UC Davis

Christina Gillis, Ph.D., Townsend Center for the Humanities, UCB

John Gillis, Ph.D., Dept. of History, Rutgers University

Jim Goldberg, photographer

Frank Gonzalez-Crussi, M.D., pathologist, Children's Memorial  
Hospital, Chicago

Gayle Greene, Ph.D., Dept. of Literature and Women's Studies, Scripps  
College

Blanche Grosswald, School of Social Welfare, UCB

Marita Grudzen, M.H.S., Stanford School of Medicine

Jodi Halpern, M.D., Ph.D., UCB/UCSF Joint Medical Program

Pamela Jones, Dietician, Consultant

Theresa Kingston-Bonney, Dept. of American Studies, UCB

Gary Laderman, Ph.D., Dept. of Religion, Emory University

Ernest Landauer, Bay Area Funeral Society

Shai Lavi, Doctoral Candidate, Jurisprudence and Social Policy, Boalt  
Hall School of Law, UCB

Sarah Liu, Ph.D., Dept. of English, UCB

Judith Martin, M.D., The 14th Street Clinic

Alec McLeod, California Institute of Integral Studies

Guy Micco, M.D., Alta Bates Hospital and Joint Medical Program,  
UCB/UCSF

Desi Owens, M.S., M.S.W., Institute for Health and Aging, UCSF

Jamie Pehling, UCB/UCSF Joint Medical Program

Linda Ramos, University of Colorado, Boulder

Jose Rodriguez, Ph.D., Communication Studies, CSU Long Beach

Katarzyna Rolzinski, Ph.D., California Institute of Integral Studies

Anne Julienne Ross, Ph.D., Post-Doctoral Fellow, UCB

Paul Sarvasy, M.D.

Lawrence Schneiderman, M.D., bioethicist, UCSD

Rachel Schochet, Psychologist

Madelon Sprengnether, Dept. of English, University of Minnesota

Liz Susman, Funeral Consultant, SF General Hospital and Kaiser,  
Oakland

Debu Tripathy, M.D., oncologist, UCSF

Charles Webel, School of Social Welfare, UCB

Joanna Weinberg, J.D., L.L.M.

Michael Witmore, Ph.D., Dept. of English, Carnegie Mellon University

Monica Worline, Organizational Psychology, University of Michigan

## Appendix Three

# Conference Speakers

**Patricia Benner**, R.N., Ph.D., is Professor of Physiological Nursing at UCSF and has written extensively on issues in critical care. Recent articles include “A Dialogue between Virtue Ethics and Care Ethics” and (co-authored) “The Nurse as a Wise, Skillful and Compassionate Stranger.” Book-length publications include *Caregiving: Readings in Knowledge, Practice, Ethics, and Politics* (co-edited) and *Clinical Wisdom and Interventions in Critical Care: A Thinking-In-Action Approach* (co-authored).

**Thomas Cole**, Ph.D., is Professor of History at the Institute for the Medical Humanities, University of Texas Medical Branch, Galveston, Texas. He is the author of the classic history of aging, *The Journey of Life: A Cultural History of Aging in America*. His current project is a documentary film entitled *Anatomy and Humanity: Conversations with Donors and Dissectors*.

Poet and essayist **Sandra Gilbert**, Ph.D., is Professor of English at UC Davis. She has published numerous works of poetry, including *Emily's Bread* and *Ghost Volcano*; the list of book-length publications includes the classic feminist study, *The Madwoman in the Attic: The Woman Writer and the Nineteenth-Century Literary Imagination* (with Susan Gubar), and *Wrongful Death: A Medical Tragedy*.

San Francisco based photographer **Jim Goldberg** has exhibited his work in numerous solo shows around the United States and in Europe. In *Raised by Wolves*, he took up the lives of children on the streets; in his contribution to the Hospice show, originally mounted at the Corcoran Gallery in Washington, and later published in the catalogue, *Hospice: A Photographic Inquiry*, he focuses on the death of his father.

**Frank Gonzalez-Crussi**, M.D., is Professor of Pathology at Northwestern University Medical School (emeritus) and Head of Laboratories at Children's Memorial Hospital of Chicago. In addition to his extensive publication in medicine, Dr. Gonzalez-Crussi is the author of *The Day of the Dead and Other Mortal Reflections*, *Notes of an Anatomist*, *Suspended Animation: Six Essays on the Preservation of Bodily Parts*, and *There is World Elsewhere: Autobiographical Pages*.

**Jodi Halpern**, who holds the Ph.D. in Philosophy as well as the M.D., is Assistant Professor of Medical Humanities in the UC Berkeley/UCSF Joint Medical Program. She has published numerous articles in the field of clinical ethics and is the author of *Beyond Detached Concern: Empathy and Respect for Patient Autonomy in Medicine*.

**Gary Laderman**, Ph.D., Assistant Professor in the Department of Religion at Emory University, is a historian of American culture and religion. His first book, entitled *The Sacred Remains: American Attitudes Toward Death, 1799-1883* was published in 1996; he has recently completed his second book, *Death in Modern America: A Cultural History of the Funeral Home*.

**Guy Micco**, M.D., Clinical Professor of Medicine in the UC Berkeley/UCSF Joint Medical Program, says that he has been interested in the problem(s) of death for "as long as [he] can remember." A primary care physician in Berkeley, Dr. Micco serves as Chair of the very active Ethics Committee at Berkeley's Alta Bates Hospital. He is also Director of the Center for Medicine, the Humanities, and Law, recently organized on the Berkeley campus.

**Lawrence Schneiderman**, M.D., is a Professor in the Department of Family and Preventive Medicine and the Department of Medicine at the School of Medicine, UC San Diego. Dr. Schneiderman is a founding member of the San Diego Bioethics Group, and his many publications in that area have focused on debates over fertility issues at the end of life, the role of the family physician in end-of-life care, decision making about medical care with critically ill patients, and the impact of pediatric ethics consultations on patients, family, social workers, and physicians.

Oncologist **Dr. Debasish Tripathy** is Associate Clinical Professor of Medicine at the Mount Zion Breast Care Center, UCSF. The author of many scientific papers, Dr. Tripathy is a contributing editor to *Breast Diseases: A Year Book Quarterly*. He also serves on numerous civic and community boards concerned with issues around breast cancer.

**Michael Witmore**, Assistant Professor of English at Carnegie Mellon University, earned his Ph.D. in Rhetoric at Berkeley and is completing his book, *Culture of Accidents: Unexpected Knowledges in Early Modern England* (forthcoming from Stanford University Press).









