Dementia-Near-Death and “Life Itself”

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This chapter is about the cultural work that dementia does, the sociomedical uses to which it is put in the American hospital at the end of life. I suggest that dementia works there in three ways: as a rationale for facilitating death, as a contested feature of what matters about the patient’s identity, and as a moral-clinical designation of value when a frail life is perceived to hang in the balance. In performing this multiplex work, dementia makes manifest one aspect of the ethics and politics of life itself in the negotiations it elicits about “quality of life,” “loss of personhood” and “diminishing life”; in debates about what constitutes “normal” and “natural” decline toward death; and in cultural ambivalence about whether the end of “meaningful life” is reason enough for death.¹ Dementia has entered the domain of choice; to confront dementia is to be faced with options for maximizing function, minimizing suffering, and organizing care. Decision making is inevitable.

Moreover, dementia, as a mutable category of knowledge and cultural form, obscures the distinction between life and death. In its various stages—early, moderate, advanced, severe, and end-stage—dementia is a condition both of death-in-life and of life-in-death. This ambiguity becomes more profound as the disease progresses, and it lies at the heart of the anguish about what to do. This ambiguity is what makes dementia so compelling for families; so unnerving in the context of the cultural importance of memory, control, and reason; and so unsettling to the existing order of things.

As with other medical sites in which productive technologies are scrutinized by ethnographers, dementia-near-death brings together biomedical and socioeconomic features of contemporary American health-care delivery in novel ways to permit and create a further remapping of the notions of life,

person, and value.² Specifically, the normalization of clinical techniques to control the timing of death, the ubiquitous structural imperative of patient and family decision making, quandaries about the relation of the *person* to the body when disease masks or destroys normal consciousness, disputes about the goals of medicine when the end of life is imminent, and the fact that clinical interventions are possible up to the moment of death all converge at this site. That convergence has multiple effects. For example, a new kind of patient population is produced. The ethics of medical and familial responsibility are further complicated.

Canguilhem's prediction that "the science of life no longer resembles a portrait of life" (1994, 317) is a useful starting point for thinking about dementia as a form of cultural production and, more broadly, for adding to an anthropology of "life itself." In their histories of the modern life sciences, Canguilhem and Michel Foucault point out that the concept of *life*, as a specific object of knowledge, to be known through the modern biological sciences, did not exist until the end of the nineteenth century. Foucault writes, "Historians want to write histories of biology in the nineteenth century; but they do not realize that biology did not exist then, and that the pattern of knowledge that has been familiar to us for a hundred and fifty years is not valid for a previous period. And that if biology was unknown, there was a very simple reason for it: that life itself did not exist. All that existed was *living beings*, which were viewed through a grid of knowledge constituted by natural history" (1970, 128; *italics added*).

The idea that life as a process, mechanism, and structure could be studied (and perhaps ultimately understood) owes its emergence to the rise of theories of evolution and owes its expansion to concepts formed through the sciences, first physiology, and more recently molecular biology and genetics (Canguilhem 1994; Franklin 1995). Importantly, by the mid- to late twentieth century, knowledge of the living body and the forms and structures that constitute life, especially DNA or the genetic code, "became intrinsically linked to interventions that transformed those living bodies" (Rose 2001). Life, health, illness categories, and death were objects to be acted on via the instrumentalization techniques that the biological sciences and clinical medicine offered (Franklin 2000; Rabinow 1996, 2000).

Here I explore how cultural meanings about aging, senescence, dementing illness, and the "natural" life span are inscribed in biological materiality and the biomedical techniques that enable us to know what life is. The biological and biomedical, in turn, shape understandings of how the person with dementia is bodily (that is, fundamentally) constituted and provide moral and socio-economic frames for the range of interventions. Uttered today as a gloss for any neurological condition that slowly or rapidly destroys cognition, memory, reflexivity, and expressive capacity, dementia is a modern form of life itself, in the sense that biomedical and related apparatuses are brought to bear on a diag-

nosed condition, transforming "living beings" into victims, patients, and research subjects with a degenerative brain disease and rationalizing a host of management strategies.

The Changing Relationship of Old Age and Dementia

That both the nature of aging itself and the relationship of old age to dementia have been debated for well more than a century is significant for the contemporary fact that (in the United States at least) dying requires certain kinds of decisions and interventions in order to be considered "good," "natural," or "humane." Whether normal aging is a disease, whether senility in old age is normal, and whether aging per se leads inevitably to death are all questions that persisted long before recent forms of medicocultural negotiation emerged. Although the terms of the debate have shifted since the nineteenth century with the growing sophistication of biological knowledge and with changes in the politics of medical science and the structure of health-care delivery, the debate itself is ongoing (Holstein 1997).

Once a synonym for old age, by the late nineteenth century, the term *senility* referred specifically to the weakness and decrepitude that characterize old age, and it gradually gained pathological connotations (Achenbaum 1978; Cole 1992; Haber 1984). The gradual shift in the perception of senility gave rise to a medicocultural site for debates about the classification of symptoms, behaviors, and old age itself and, especially, whether old age was a normal physiological process or a pathological condition. When, in 1907, Alois Alzheimer described the clinical condition that bears his name, dementia associated with old age was still considered a normal, expected part of age-related decline. The normal aged body, regardless of how healthy or diseased, was characterized by that particular pathological sign (Herskovits 1995; Katz 1996, 44). "If old age was a period of progressive decline, then the signs and symptoms of dementia were expected, if not inevitable, a "normal" correlate of old age. Thus, in what may seem contradictory to modern readers, turn of the [twentieth] century investigators often described 'normal' aging somewhat quixotically as pathological . . . in this way, dementia could be simultaneously 'normal' and 'pathological'" (Holstein 1997, 7).

Physicians practicing at the beginning of the twentieth century found it almost impossible to separate ordinary, normal changes of late life from organic brain disease. In 1909, I. L. Nascher, the New York physician who coined the term *geriatrics*, aimed to separate the concepts of *old age* and *disease* and cut through the debate of the period with the assumption that old age is a normal condition (yet one requiring distinctive medical attention). He sought, following Charcot, to separate "normal senile degeneration" from pathological "softening" of the brain. Yet the separate explanations of *normal* and *pathological*

offered in his foundational text of 1914, *Geriatrics*, are muddled, and he found the task of clinically distinguishing normal degeneration from pathological signs to be impossible (Cohen 1998, 64). Nascher's work, though authoritative in the United States, did not provide definitive clarification about relationships between advanced age, dementia, and decline at the end of life. Debates about pathology and normalcy in old age, especially vis-à-vis mental disease, continued. One theory of aging as a chronic disease was taught in American medical schools at least until the late 1930s (Cole 1992, 207). In the period between World Wars I and II, two opposing views of old age competed for acceptance in American medicine: "One school considered 'senility' a pathological disorder; the other described it as a normal physiological state. In 1941, it remained 'a major problem for science to determine which is correct'" (Gray [1941] cited in Achenbaum 1978, 120).

The move from "senility" to "senile dementia" to "Alzheimer's disease," well documented as the medicalization of senility by social scientists (Fox 1989; Holstein 1997), indicates the gradual decoupling of normal aging from distinct brain pathology. Yet debate remains lively today in clinical medicine and gerontological science about whether Alzheimer's disease is a distinctly pathological state or a quantitative extreme of normal aging (Herskovits 1995). The plaques and tangles that characterize the disease can be seen as well in healthy elderly brains on autopsy and sometimes are not present in the brains of those diagnosed with Alzheimer's. In addition, some of the behavioral symptoms of Alzheimer's (especially those of forgetfulness) can be found in normal, healthy older persons (Drachman 1983; Goodwin 1991; Gubrium 1986). Attempts to distinguish normal aging from discrete medical conditions of the brain plague contemporary researchers and clinicians. Ambiguity about which conditions are normal or pathological is reflected in recent titles from the geriatric and gerontological literatures, such as "Dementia of the Aged: Disease or Atypical Accelerated Aging?" "Geriatric Ideology: The Myth of the Myth of Senility," and "Aging versus Disease: Which Changes Seen with Age Are the Result of Biological Aging?"

The idea of *age-related disease* muddies the waters further and is of interest here because aging and disease, separately or together, can cause death. Arteriosclerosis and the decalcification of bone, for example, are expressions of normal, ordinary human aging "until they progress to a point at which they lead to diseases such as heart attacks, strokes, osteoporosis and renal disorders. How one identifies the point of transition is not clear" (Blumenthal 1993, 1272). Arteriosclerosis can be thought of as disease or as normal aging, depending on the definition of aging (Forbes and Hirdes 1993). Some scientists and clinicians propose that aging and disease be viewed as a continuum rather than as discrete categories, using the example that there may be a continuum of brain lesions from normal aging to Alzheimer's disease just as there is a continuum of arte-

riosclerotic changes from normal to disease entity (Forbes and Hirdes 1993; Von Dras and Blumenthal 1992). For instance: "[F]rom the biopathological perspective, virtually all of the lesions associated with dementia . . . are commonly seen in the non-demented aged as age-dependent lesions. And in both non-demented and demented subjects various combinations of these are also commonly encountered. . . . The aging-disease relationship with respect to dementia has also been regarded as a threshold phenomenon in which dementia occurs when aging changes exceed a particular limit" (Von Dras and Blumenthal 1992, 286).³

Dementia, Death, and Value: The Ethics of *Life Itself*

While those debates continue, they have been joined in recent years by a new set of concerns about the relationship of dementia to death, to quandaries over life prolongation, and to the widespread desire and bureaucratic need to control the timing of death. These concerns are born of the fact that, first, feeding tubes, antibiotics, and surgery of all kinds can and do extend demented lives for prolonged periods; and, second, memory, consciousness, and the modern task of self-making are considered essential to being fully alive (Cranford and Smith 1987; Foucault 1970, 1974; Giddens 1991; Taylor 1985). Dementia has entered the domain of the ethical because the "fact" of the *person* can be questioned and because, often, death is a matter of a decision. One must choose. The discourse of apocalyptic demography—namely, Alzheimer's is "the disease of the century"—coupled with the widespread fear of losing one's mind, feeds concerns about whether, and when, one should choose death—for oneself or for another. The late-nineteenth- and early-twentieth-century attention to the classification of symptoms as normal or pathological has been supplemented today by ethical, institutional, and economic imperatives about the classification of life-sustaining treatments as appropriate or not. Considerations of the "rightness" of prolonging life or of dying take center stage, as do evaluations of the "right" time to die and the temporal nearness to death of the demented person. These considerations are further troubled by questions about when "dying begins," the moral and clinical relevance of subjectivity to life prolongation, whether the person with dementia is still "alive," and which medical interventions contribute to or relieve "suffering." *Dementia-near-death* problematizes the subject in an unprecedented way.

Inescapable today is the fact that demented life (as all forms of *life itself*) is the object of debate about value; it must be accorded a value. The "new ethics of biomedical subjectivity" (Novas and Rose 2000, 502; Rabinow 1996, 2000) can be characterized by disputes over value, which are made apparent, first, in the ubiquitous discourses of "quality of life," "the right to know," the "right to choose," and "risk assessment" that penetrate so deeply in the affluent sectors

of Western societies and, second, in the life strategies opened up through biomedical techniques (such as assisted reproduction, genetic screening, mood-altering drugs, and plastic surgery). One's biological destiny, and that of one's progeny, is no longer fixed and immutable. Prevention, enhancement, and intervention are possible, even into advanced age. We can choose, and it is our responsibility to choose, because biomedical technique has extended choice to every aspect of existence (Rose 2001, 22), including the timing of death. In the case of dementia-near-death, death in the hospital is facilitated or postponed according to a negotiated calculus about the value of a particular kind of vulnerable life in relation to assumptions about the nearness of that life to death.

The Clinical Articulation of *Forms of Life*

The disease category *advanced dementia* is a window onto changing knowledge about the organization of *life itself*, and those changes are revealed in the ways clinical medicine grapples with what to do (because it must do something) in the face of death. Two examples highlight the unstable understandings of this form of life:

1. In response to the exponential growth of the use of feeding tubes in persons with advanced dementia, therapeutics took a stand in 1999–2000 and changed course. The *Journal of the American Medical Association* and the *New England Journal of Medicine* published statements reflecting new medical thinking about the treatment of that condition. Contrary to standard U.S. clinical practice of the preceding two or three decades—which had considered tube feeding by percutaneous endoscopic gastrostomy (PEG) as appropriate therapy to prevent aspiration pneumonia, prolong survival, reduce risk of pressure sores or infection, improve function, and provide “comfort”—academic clinicians and geriatric researchers decided that tube feeding did none of those things (Finucane, Christmas, and Travis 1999; Gillick 2000). Evidence had accumulated from a series of clinical studies that food and water given by feeding tube to persons with advanced dementia caused rather than ameliorated suffering and did not contribute to the extension of life, regardless of whether that life was considered “meaningful” by any standard. Thus tube feeding was no longer appropriate and necessary medical care for persons with advanced disease.

The authors of both articles were careful to note the limit of their claim—only in *advanced dementia* was tube feeding no longer medically indicated. Yet in their reflections on the clinical evidence, the writers of both these state-of-the-art articles made sense of advanced dementia in a new way—as a form of life that has lost all potentiality except the move toward death. Its reconfigured characterization, being near death, justified

and rationalized the withholding of nutrition and hydration at the same time as it reorganized value about this kind of life. This general pronouncement, however, did not immediately eradicate or ease dilemmas associated with the goals, on the ground, of caring for any individual patient or one's own family member.

2. In a study to examine treatments and survival of patients with "end-stage dementia" following acute illness, researchers documented the interventions received by 216 hospitalized patients. The rationale for conducting the study was as follows: "An estimated 1.8 million people in the United States are in the final stages of a dementing illness (e.g., Alzheimer disease, vascular dementia) and are unable to recognize family, dependent in activities of daily living, unable to communicate, and experience repeated infections and other complications. Despite the prevalence of advanced dementia, little is known about the prognosis of patients with this condition who develop a superimposed acute illness (e.g., pneumonia)" (Morrison and Siu 2000).

The researchers found that advanced dementia is not viewed as a terminal diagnosis by physicians or families, that patients with end-stage dementia receive "as many burdensome procedures as cognitively intact patients," and that there is an absence of awareness about the poor short-term prognosis for these patients. They suggest that efforts be turned to the provision of palliative or comfort, rather than life-extending, measures.

Both these examples reveal how clinical medicine is working out an understanding of and an approach to this form of life. Moreover, both engage, at the same time as they attempt to end, one aspect of the societal debates about what forms of life are worth sustaining, why, and for how long.

In a different sort of articulation expressed beyond the clinic, *advanced dementia* is juxtaposed with *early dementia*. Both designations, *early* and *advanced* dementia, are noteworthy for the distinctive ways in which they reorganize societal understanding of this disease by incorporating death into their schema. *Early* dementia further specifies this form of life that pushes decline, disease, and death earlier into the life course. On the one hand, the specter of genetic testing opens the possibility of "living with" dementia for years prior to the appearance of any symptoms. On the other hand, contemporary understandings—that the disease progresses via the loss of abilities acquired during infancy and early child development—brings death into life slowly. It is generally acknowledged that the death of the *person* and the *self* will occur in stages that can be differentiated over a protracted period of time. *Life* will diminish via a pattern of developmental regression (Reisberg 1999; Shenk 2001) at the same time that *death* will advance within the person and the person's body.

Dementing illness is widely characterized as a process that slows down

death. The novelist Jonathan Franzen (2001), reflecting on the death of his father from Alzheimer's, notes that the disease is like a prism that refracts death into a spectrum of its parts: death of autonomy, death of memory, death of self-consciousness, death of personality, death of the body. These features of the disease can be considered separately, even when they are observed to occur together, so that the phased death of the demented person is exquisitely described as the disease worsens. With the diagnosis of early dementia, the process of dying takes place over decades and is reflected in such well-worn phrases as *death in life*, *death before death*, and *never ending death*.

When the condition becomes *advanced* and is accompanied by other life-threatening illnesses, consideration of techniques for allowing death vie with those of prolonging life, as the preceding examples from the medical literature show. The medical pronouncements, that tube feeding is no longer humane or efficacious for extending life and that comfort measures should be employed for end-stage disease, are often irrelevant for family members struggling to sustain a valued life. Those pronouncements are sidelined by staff concerned with honoring family demands. Moreover, in the hospital, that new knowledge cannot compete with the initial press to prevent death. Most often death is not named as possible or inevitable until shortly before it occurs. Thus, when death is finally pronounced as an impending truth by medical staff, the "choice" to withdraw or withhold therapies makes dying appear, to families, to be "speeded up."

Negotiations about Life when Death Is Near

I now turn to ways in which dementia is invoked and ignored in the hospital at the end of life and the ways in which knowledge about the demented person, disease, life itself, and the worth of a particular life come together for negotiation. The hospital practices in which dementia is implicated provide one example of how clinical medicine governs the end of life and how death is elided with ways of knowing life. The following two stories of patients' pathways to death are common, and they reveal the tensions surrounding the protection, extension, manipulation, and demise of that kind of life. Highlighted in these stories are the "choices" confronted by family members, who often feel they are being asked to choose between "life" and "death," as though those notions were equally weighted. Confusion between inexorable decline, possibly hastened by dementia, and disease that may be arrested by medical interventions confounds that choice, and families often refuse to choose anything at all. Staff, by contrast, feel the pressure of the hospital system to move things along to death when they know it is inevitable. Within the rules and norms of the hospital world, families and medical staff each engage the patient's life with different sensibilities about the relevance of dementia, along with other signs of end-stage disease, for calculating an appropriate time for death.

Acute Disease, Heroic Intervention, Organized Death: Dorothy Mason

HOSPITALIZATION, DAY 1: At ICU (intensive care unit) rounds, I follow the team to the bed of Dorothy Mason, and the doctor tells me that she arrived last night from a nursing home with "bad pneumonia, bad lung disease, and Alzheimer's disease. I don't know how she got here," he says, "but her son was with her. He wants everything done." The nurse assigned to her tells me, "If this were my mother, I'd let her go. I don't know why the son is doing this—guilt? need? If she doesn't get better, the doctors will begin to talk to the son about taking her off the mechanical ventilator and letting go, but not until she doesn't start to get better." Another nurse says, "She came from the nursing home extremely malnourished, weighs seventy-five pounds, and looks like she arrived from Auschwitz." All I can see is the head of a very frail old woman who is connected to a breathing machine and to several intravenous lines for fluids and medications. Mrs. Mason is seventy-nine years old. Someone at the nursing home called the paramedics when Mrs. Mason was observed to be in respiratory distress; she was brought by ambulance, with high-flow oxygen, to the hospital emergency room and intubated there.

DAY 2: The lens through which all hospital patients are viewed is colored by the imperative to move them efficiently along one of several treatment pathways—to life-saving treatments, to cure or stabilization, or to death. Several nurses sketch a sociomedical portrait of Mrs. Mason for me. "She's a 'no code,' but still on the vent and getting nutrition and care. We just won't do CPR [cardiopulmonary resuscitation]," I am told. Another nurse says, "She was made a no code at 10:00 P.M. last night. Up to then the son wanted everything done. The doctor talked to the son earlier, then at nine o'clock last night he went to him again, explained the situation again, and asked him, 'Would you really want us to pound on her chest and crack her ribs?' That's when the son reluctantly agreed it was OK to make his mother a no code." Later, the nurse on the evening shift says, "The son made the decision to continue full-out antibiotics for twenty-four hours. If there is no improvement by tomorrow, he'll consider withdrawing care. He has moved a lot, from thinking she was a viable hospital patient to acknowledging that she might die. He's come far."

DAY 3: There is no improvement. Mrs. Mason is not responsive, though her eyes open sometimes and she seems to look around the room, but nurses tell me that she cannot purposefully move her eyes; there is no intent behind the look, no *person* behind the stare. That clinical judgment—that the patient is not fully, really alive—often contradicts the opinion of family members, who tend to see purposefulness in small movements and to think that the conscious person they knew before the crisis is still there, hidden within a sick body.

Mrs. Mason's son wants to continue antibiotics for an additional twenty-four hours to "see what happens" and then consider withdrawing life-sustaining treatments. The patient's nurse for today confides to me: "She should never have been put on a ventilator in the emergency room. She should have had a nasal cannula, and then she would have eventually died, peacefully. . . . She has had Alzheimer's disease for a long time and has been incontinent for a long time. She came in with bilobar pneumonia [pneumonia in both lobes of the lungs]. In the nursing home they weren't treating it, which was wise on their part, but she wasn't supposed to die, because she wasn't made a no code." The nurse goes on to say that it is difficult for Mrs. Mason's son to see anything other than a strong mother who has bounced back before: "She had been sort of moving along, incontinent, demented, getting more frail, with lousy nutrition, but not that sick. This is the first time he's seen her really sick, maybe going to die. So he can't accept it at first."

DAY 4: At the bedside I speak with Mrs. Mason's son for the first time. He is sitting close to his mother's bed and looking at her tenderly, talking to her and holding her hand. She is unresponsive. He tells me, "She had a living will done about eight years ago, and in it she was clear that she didn't want her dying prolonged. Now it's tough in the hospital because she couldn't have predicted this sort of a situation and I don't know if this is prolonging her life." He had been with her in the nursing home when the nurses there called 911. He had come to the hospital with her. The doctors in the emergency room needed to know immediately if they should intubate her because without mechanical ventilation she would have died. With tears in his eyes he reports that he said, "Yes, go ahead," because he wanted her to live, was hopeful she would stabilize, and could not accept being singled out to be responsible for her death at that moment. Although he made that decision quickly, he tells me he agonized over it. "It isn't her time yet," he says and tells me she had been hospitalized a year earlier and had "come back" from other crises. "She is tough." But he would not want her to live indefinitely on a ventilator and neither would she. He only wants her to have the opportunity to get better, to get off the ventilator.

"You're not seeing the really tough decision points," he tells me. "They happened earlier. My toughest decision was moving her from home to assisted living eighteen months ago." She had covered up her Alzheimer's disease well. "She was social and she had a good sense of humor." He knew things were changing, but he did not know how bad things were until about a year ago when he moved her to the nursing home and she was diagnosed with advanced Alzheimer's. Regarding the hospital requirement for a "code status" decision, he volunteers that he made his mother a no code. He says to me, "Some families might think making a no-code decision is participating in killing the patient, but I don't think so." (He does not mention what I was told two days before by

the medical and nursing staff, that he had had to be talked into making that decision.)

DAY 8: The nurse calls me to the bedside, dramatically pulls the sheet off Mrs. Mason, and says, "Look at this." She has been trying to turn Mrs. Mason and is having a great deal of difficulty. Mrs. Mason's limbs are so contracted, her legs so tightly wrapped around one another, that the nurse cannot disentangle them. Mrs. Mason is not responding to the nurse's maneuvers or to our conversation. I am looking at emaciated legs with the skin hanging directly on bones that look brittle, as if they would shatter if they were touched. I have never been this close to such frailty.

DAY 10: Mrs. Mason's son continues to want "aggressive" care, that is, continued mechanical ventilation, nasogastric tube feeding (use of a thin tube inserted through the nose that delivers nutritional liquid to the stomach), and antibiotics for the recalcitrant pneumonia. The medical staff is trying a different antibiotic. I go to Mrs. Mason's bedside with a technician who is going to draw her blood. He speaks to her in a loud but caring voice, close to her face, telling her what he is going to do, and she turns her head to stare at him. I reintroduce myself, and she turns to me and stares. But she does not respond in any other way or even blink.

At the bedside I speak again with Mrs. Mason's son and also with her daughter, who has just arrived from another state. Mrs. Mason is looking at her children, that is, her eyes seem to focus on them, but I cannot be sure. It is impossible for me to tell if she is hearing and then comprehending our conversation, because she is so unresponsive. The nurse comes in to draw her blood. Mrs. Mason's son and daughter both repeat to me that they do not want their mother to be on life support. I am not sure if they realize that their mother is, indeed, on life support.

DAY 12: The intensive-care doctor mentions to me that Mrs. Mason's kidneys and other organs are beginning to fail. Her family doctor discusses her failing condition with her children for some time and urges them "to withdraw ventilator support and let her die." They listen and agree. She dies shortly after the ventilator is withdrawn, with her children, the family doctor, and the intensive-care specialist at her bedside.

Slowing Diminishing Life, Debate about Life: Nhu Vinh

BACKGROUND: Mrs. Nhu Vinh's medical condition was not unusual; nor was the response to it of her daughter, Mrs. Tran. Mrs. Vinh, age eighty-four, had been diagnosed with Parkinson's disease six years before her current hospital-

ization, though in retrospect, Mrs. Tran tells me, her mother had had symptoms long before the diagnosis. Shortly after her diagnosis, she needed round-the-clock care at home, which Mrs. Tran arranged with attendants. But, Mrs. Tran says, her mother still had “quality of life.” She could go out to family functions and enjoy herself. The past two years, however, had become much more difficult as the disease had progressed. Mrs. Tran relates the story of her mother’s decline while we sit together in her mother’s hospital room. She has just washed Mrs. Vinh’s long gray hair and is spreading it out across the pillow as her mother lies sleeping. It is a warm day and Mrs. Tran has turned on a fan to help dry her mother’s hair. Mrs. Vinh is breathing through a nasal cannula. Her hands, visible above the sheets, are extremely contracted.

In the months before her hospitalization, Mrs. Vinh could not walk. It took three or four hours to feed her each meal. The attendants, whose work Mrs. Tran supervised closely, would spoon pureed food into her mother’s mouth and they were extremely careful to watch that she swallowed each mouthful. Mrs. Vinh had become incontinent and demented. But she could still interact with her daughter. Six weeks before I met the patient and her daughter in the hospital, the home attendants, doctors, nurses, and speech therapist who were caring for Mrs. Vinh all agreed without debate that Mrs. Vinh was not getting enough nutrition and needed a feeding tube inserted into her stomach.

Mrs. Vinh had the routine, low-risk, low-tech procedure to insert what is known as a *g-tube*. But since that time, Mrs. Tran tells me, her mother has had nothing but problems, especially recurring reflux and fevers. Mrs. Tran says with pride that in the two years prior to the insertion of the tube, her mother was not hospitalized and nothing had ever gone wrong.

ADMISSION TO DAY 6: After six weeks of problems following the placement of the feeding tube, Mrs. Tran admitted her mother to the hospital. Mrs. Vinh had pneumonia from aspirating her own secretions, and in addition the *g-tube* had accidentally moved (“migrated,” in medical language). Upon admission to the hospital, physicians treated the pneumonia and suggested replacing the *g-tube* with a tube inserted into the jejunum (*j-tube*), the small bowel, in order to avoid the regurgitation and possible aspiration of food into the lungs.

The procedure would require general anesthesia, and Mrs. Tran debated, along with her large extended family, whether the surgery was the right thing to do. They finally decided to go ahead with it. “This was a very, very hard decision, because we knew she was a high-risk surgical patient,” she tells me. Mrs. Tran is adept at quickly translating her way of knowing into language that American health-care providers can easily understand, and she explains that for her family, as Buddhists, and as Asians, the decision was not based on quality-of-life considerations—“My mother hasn’t had any quality of life for two years.” The family simply wanted to prolong Mrs. Vinh’s life. However, they did not want to

do anything that would create pain and suffering. They had decided previously that Mrs. Vinh would not be put on ventilator support if she could no longer breathe on her own, and she would not be subjected to CPR if her heart stopped beating. Other than that, her life should be maintained. Mrs. Tran explains these decisions and adds other things she wants me to know about her. Her father had been a well-regarded Buddhist practitioner. She had come to the United States from Vietnam thirty-five years ago. Her very young grandchildren, she says proudly, speak Vietnamese. She has a disabled cousin whose care she supervised for many years. She herself works in a health profession and has taken a leave to care for her mother. She is spending most of her time, day and night, at her mother's bedside.

DAY 7: The surgery, which took place the day after Mrs. Vinh was admitted to the hospital, was not complicated, but Mrs. Vinh has not been doing well since then. She has not regained her previous physical condition and mental state, as the medical team and family had hoped. The doctors treating her have written in her medical chart, "end-stage care," "dementia and chronic vegetative state," and "continues to deteriorate." The physicians tell Mrs. Tran that her mother's condition is deteriorating, that she will not survive. She was still aspirating, despite the j-tube, so she could not be fed through it, and Mrs. Vinh is now receiving antibiotics, food, and morphine through an intravenous line, a situation that cannot go on indefinitely.

Expressing both her convictions and her ambivalence, Mrs. Tran tells me, "My mother is a fighter. She wants to live. I know this about her very deeply. All of this talk about quality of life is not relevant. She wants to live, even in this condition; that is why she struggles to breathe so much; that is why they gave her the morphine, to make her breathing easier. But I don't know. Maybe they just should give her more morphine till she stops breathing. . . . I want her to live, but I want her to be comfortable." Mrs. Tran's brother is on his way to the hospital from his home in another city. Mrs. Tran says that her mother is waiting to die—waiting for her son to come and see her.

Now, six days after the surgery, the medical team wants to stop giving Mrs. Vinh infection-fighting medications and move her along to her death. They assume she is not conscious and know she is at the end stage of her disease. They see no reason to prolong her dying and perhaps cause her to suffer. They want to create a comfortable death. The hospital social worker tells Mrs. Tran that the staff wants to meet with the family as soon as her brother arrives. Mrs. Tran, quite familiar with predictable (and desired) hospital pathways, asks rhetorically, "Why do they want to have a meeting? We've already made her DNR [(do not resuscitate) order] and no intubation. I am ready to take her home if she can be discharged. I can handle it. I am set up for it with new caregivers. My mother didn't have oxygen at home before, but we'd get it this time, and I'd learn how to

do it. This is not a problem. We've discussed everything already. There is no need for a meeting. Why do they want a meeting? It's because they want to tell me that if they take off the oxygen mask she'll die more quickly. That leaving on the mask is prolonging her life. It's just like the ventilator. If you remove the mask, she'll live maybe a few hours, or a few days or a few weeks, but she'll die sooner. That's why they want to have the meeting." Mrs. Tran is quite aware that the medical team views her as the obstruction to a quicker death.

The Vinh family conference was scheduled to take place as soon as the son arrived. The conference follows the standard format for medical staff communication with families: medicine speaks what it understands to be the truth about the patient and outlines the proper course of events, and the family is expected to understand, to agree, and "to get with the program." The doctor, an immigrant from China, speaks first and begins by reviewing the patient's medical condition. He is thoughtful and describes her condition as best he can.

MD: We removed the g-tube but now your mother is having problems with the j-tube. We're treating her with antibiotics. She was in the ICU for a day or two, intubated. She still has pneumonia. That is not going away. She still has off-and-on fevers. Her breathing is more labored, more fast and shallow, because she doesn't have enough oxygen in her lungs. Basically, I'm sorry to say, she's not doing well, and I want to give you a true picture. This situation is difficult for everyone and for the medical profession as well. I'm afraid she's going to die very soon. She almost died already a couple of times. We have no way to treat her condition. I'm afraid she's going to keep aspirating because of her secretions, even if they suctioned her around the clock. Regarding her nutrition, we are hoping the j-tube will work. But meanwhile we're giving her IV [intravenous] feedings—it is life support. We can do this short term but not long term. To me this is not in her best interest. She's not communicative. She is demented. We can keep her alive a little while, though even with the best management, she can die anytime. There's really no good treatment for her difficulties. My recommendation is that we should keep her comfortable, keep her mouth from getting dry. I recommend that we cut down on the oxygen. She's getting fourteen liters at the moment—that's a lot. And stop the antibiotics and let her go to sleep. Let nature take its course. I'm very sorry. She's lived a full life. She's very near the end of her life at this time. There's no more quality of life. Most people in her condition would have died by now.

MRS. VINH'S SON: Quality of life?

MD: She's not aware of her environment. She doesn't demonstrate anything. She cannot respond in any meaningful way.

MRS. TRAN: Sometimes, in rare moments, when she opens her eyes, when she

hears me talking she turns her eyes toward me. So we can't say that she's totally unconscious. I believe she recognizes my voice.

SON: If you don't stop any treatments how long will she live?

MD: I don't know. Days, hours, months. Her GI [gastrointestinal] tract is not working. She can't absorb nutrients. Antibiotics are not keeping the fever under control.

SON: Is she's suffering? She's not conscious, as you say.

MD: She's not getting pain medications or sedatives.

MRS. TRAN: We are giving her morphine.

SOCIAL WORKER: Are you worried about her comfort level?

SON: I'm basically wanting to know if she is alive. Is she conscious? Is she's suffering?

MD: Well, her body is alive; you're keeping it alive. Her consciousness is minimal. There are gradations of this, of consciousness.

MRS. TRAN: But she's been like this for years.

MD: As far as suffering, I don't think she's in pain, but I can't know for sure. Even if we do everything, I don't know how long she'll live. Most families won't keep someone alive on tube feeding.

SON: What is your recommendation?

MD: Let nature take its course.

SON: What does that mean?

MD: Stop the feeding and antibiotics. Give her a little oxygen for comfort only. Give a little morphine for pain. But let nature take its course. Even with the current treatments, I don't think she'll live more than a few days.

SON: We have some family members missing. We want to meet as a family.

MD: She's in limbo land, between life and death. Regardless of our interventions, she'll die.

SON: It's very important that she has all the comfort.

(The doctor leaves the room.)

CASE MANAGER: Absolutely, that's what we want to do.

MRS. TRAN: So we can't talk about discharge?

SOCIAL WORKER: The doctor's job was to give you the medical picture and his recommendations.

MRS. TRAN: Does she have to be hospitalized?

SOCIAL WORKER: That's a hard call. The fever is an issue. Could we set this up at home? You'd have to be trained.

MRS. TRAN: We're talking about a short time until she dies, regardless of what we do; that's what he said. Right?

SOCIAL WORKER: Yes. If you withdraw some of these things we can predict more closely, maybe. But if you keep all the interventions we cannot predict. Whatever you decide we'll accommodate.

MRS. TRAN: Are you in a hurry? Is there pressure? (*Looks to her brother and asks him:*) Can you make a decision now? If we withdraw everything she'll die—correct? She still has living brothers and sisters. Maybe they'll feel that isn't right. That's a big decision.

SOCIAL WORKER: How much time do you need?

SON: Two or three days at most.

MRS. TRAN: One sister is in France. A brother is in New York. You have to realize this is a difficult decision. This is a life-and-death decision. He's saying if we leave everything she'll die slower. If we remove everything she'll die faster. It's still a decision of life and death. I really feel pressure from you.

SOCIAL WORKER: I sense that. But in a few days we need to know.

MRS. TRAN: We want her home.

The conference ends and everyone stands up to leave. Mrs. Tran tells me she is going to leave the hospital for a while. She is not sure what the staff is going to do, but she is going to let her mind rest and not think about this—at least until she comes back in the evening. The social worker says that someone always takes the heat about putting pressure on families, and this time it was her turn, but she did not mind. The nurse case manager goes to see Mrs. Vinh, and it is obvious to her that she has taken a turn for the worse. She thinks the patient will die quite soon.

Two hours later Mrs. Tran leaves me a telephone message. She is crying as she says, "My mother just passed away at 6:20 P.M., and she had the elegance to pass away without her children making any decision."

Affirming Life, Allowing Death

Proactively "shortening" a life is a complicated matter. Where is the line to be drawn between giving permission to stop life-sustaining treatments and aiding the death of another? Families often conflate "not treating" with "causing" death; and that conflation is a source of the anguish that so many associate with hospital death. Most families I encountered strongly resisted authorizing death,

regardless of the specific condition of their relative. They remained hopeful that medical technology and expertise would save life and were reluctant to learn that often it fails to do so. Even though families are told that technological support is only maintaining the bodily functions, not the *life*, of the patient, unless and until they are convinced that it is certain that death will result from a medical condition, the pressure to withdraw supportive therapies can appear to be the same as or akin to outright murder. Much family resistance to staff requests for "decisions" is the result of the connection that families make between killing and withdrawing treatments.

Dorothy Mason, malnourished and with severe pneumonia and advanced dementia, suffered respiratory distress and was rushed to the hospital, where she died after twelve days on a mechanical ventilator in the ICU. Her children thought she could recover from the pneumonia despite her extreme frailty and they advocated for aggressive treatments that the staff considered inappropriate. Her son could not, would not, quickly authorize his mother's death in the emergency department, for that, from his point of view, was what he was being asked to do. Why should he authorize death when emergency medicine saves lives? He hoped for her recovery, ignored her advanced Alzheimer's, did not acknowledge pneumonia as her final illness, and certainly did not "prepare" for her death according to popularized psychosocial scripts. He pressed for continued treatment and struggled deeply with the fact that she would not, could not, be saved if she had a cardiac arrest. Doctors and nurses eventually persuaded him to authorize the DNR order that would prevent his emaciated, demented, and very ill mother from having to undergo a resuscitation attempt. But first he had to ponder for days the relationship of authorizing the DNR order to murder. Only when Mrs. Mason's family physician named death as real, told the family that their mother was clearly dying and would die no matter what, did her son assent to the withdrawal of life-support technologies.

Nhu Vinh, with advanced Parkinson's disease and dementia, was in the last stage of her illness and at the very end of her life when her daughter brought her to the hospital. Knowing her mother was near death, she nonetheless struggled to keep her alive with a feeding tube. To Mrs. Vinh's doctor, the patient was not *alive* in any meaningful sense (she lacked any expressive capability); and that "truth" was indicated by all her bodily signs, including her apparent lack of consciousness. For the doctor, Mrs. Vinh's general condition—very near death—trumped the vagaries of consciousness. For the patient's daughter, Mrs. Vinh was very much alive—she even died *elegantly*. The patient's son wanted to know the operational definitions of *quality of life*, and *let nature take its course* vis-à-vis his mother's condition, since the doctor introduced those concepts. He needed to learn whether her condition could be classified as *life*. Any attribution of suffering would flow from that designation, as would any decision on his part about terminating life. The doctor made the ambiguous point that though the

life of the patient is questionable, the family is keeping the patient (or at least her body) *alive*, and that is an *unnatural* (and perhaps pain-causing) thing to do. The patient's son remarked to the assembled group that if the staff was going to place on the family the responsibility for actively terminating his mother's life, then the relatives needed to meet as a family to gather support for such a profound act. The pressure on Mrs. Tran to allow, as quickly as possible, the removal of Mrs. Vinh's life-supporting measures was among the most extreme that I encountered. But the staff felt that they had to respect Mrs. Tran's reluctance, and if Mrs. Vinh had continued to hover at the threshold of death instead of dying shortly after the conference with the family, the health-care team would have helped set up life-sustaining care for her at home.

Physicians sometimes unwittingly offer contradictory directives to families; and a kind of doublespeak, evident in the Vinh family conference, revolves around the mystery of *life*, the difficulty of easily defining life's end point, and the fuzzy characterization of the relationship between the two notions. It emerges in the language that physicians use to explain physiological decline, the absence of beneficial treatments, and the role dementia plays in the nearness to death. It takes the following shape: "Your mother is not actually (or completely) dead, or dead yet, but neither is she alive." Or, "She's not really alive, but we can keep her alive a bit longer." Or, "He has no meaningful life, but we can continue to take care of him." Practically, *life* and *death* merge in this language. *Life* is present, but to the physician, the condition of that life indicates the inevitable transition to death. Families see unresponsive or machine- and tube-dependent patients and have no idea what to make of the gray zone in which their relative hovers. So they prefer not to acknowledge it. They are asked to make decisions, but they have too many doubts about the *life of the person* whom they can see with their own eyes. They cannot follow staff directives without substantial anxiety about what they are being asked to do.

Conclusion

Both these stories reflect routine responses to old age and disease in the United States and they exemplify common patterns of care and negotiation. In an earlier era neither Dorothy Mason nor Nhu Vinh would have been hospitalized, though specific disease labels might have been attached to their conditions. But today families must imagine *either* impending death caused by some combination of age and disease *or* treatable medical conditions regardless of age and disease. And then they must choose. Staff and family must respond to the life that is being maintained at the threshold of death by enacting what they perceive to be the most respectful and least painful passage to death *or* the best methods for continued maintenance of life. Their negotiated decisions about appropriate intervention and their desire to save life but also to facilitate the

least worst death together discursively operationalize life and reverence for it.

Conceptions of expected physiological processes as the body nears death (for example, that it is normal to stop eating); knowledge of what constitutes the normal progression of dementia toward death; and how evidence for the life of a person is to be judged, and by whom, are all at stake in those negotiations. I have illustrated at another medical site of cultural production that "choice" replaces "nature" when contested life is prolonged by biotechnologies because something can and must be done (Kaufman 2000). But it is a specific kind of moral choice: the potential or suffering or quality of life of this kind of person must be weighed against the finality (and comfort) of death. That choice both results from and affects changing medical categorizations, institutional imperatives to "speed up" or "slow down" death, and deliberation about value. In the ethics and politics of life itself, dementia is one more emergent example of a mutable form.

NOTES

1. This interpretation is inspired by the work of Nikolas Rose.
2. Among such other medical sites entailing scrutinized technologies are reproductive technologies, organ transplantation, molecular biology, and genetics.
3. See also Gubrium 1986: "It is not yet possible to clearly differentiate dementing illness from normal aging, and that the attempt to do so is a social construction to create order from the disorderly aspects of living with dementia" (50).

REFERENCES

- Achenbaum, W. Andrew. 1978. *Old Age in the New Land*. Baltimore: Johns Hopkins University Press.
- Blumenthal, H. T. 1993. "The Aging-Disease Dichotomy Is Alive, but Is It Well?" *Journal of the American Geriatrics Society* 41:1272–1273.
- Canguilhem, Georges. 1994. *A Vital Rationalist*. New York: Zone Books.
- Cohen, Lawrence. 1998. *No Aging in India*. Berkeley and Los Angeles: University of California Press.
- Cole, Thomas R. 1992. *The Journey of Life*. New York: Cambridge University Press.
- Cranford, Ronald E., and D. R. Smith. 1987. "Consciousness: The Most Critical Moral (Constitutional) Standard for Human Personhood." *American Journal of Law and Medicine* 13:233–248.
- Drachman, David A. 1983. "How Normal Aging Relates to Dementia: A Critique and Classification." In *Aging of the Brain*, ed. D. Samuel, S. Gershon, S. Algeri, V. E. Grimm, and G. Toffano. New York: Raven Press.
- Finucane, Thomas E., Colleen Christmas, and Kathy Travis. 1999. "Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence." *Journal of the American Medical Association* 282:1365–1370.
- Forbes, W. F., and J. P. Hirdes. 1993. "The Relationship between Aging and Disease: Geriatric Ideology and the Myths of Senility." *Journal of the American Geriatrics Society* 41:1267–1271.

- Foucault, Michel. 1970. *The Order of Things: An Archaeology of the Human Sciences*. New York: Vintage.
- . 1974. *Discipline and Punish*. New York: Vintage.
- Fox, Patrick. 1989. "From Senility to Alzheimer's Disease: The Rise of the Alzheimer's Disease Movement." *Milbank Quarterly* 67:58–102.
- Franklin, Sarah. 1995. "Life." In *Encyclopedia of Bioethics*. Rev. ed. Ed. W. T. Reich. Vol. 3. New York: Simon and Schuster.
- . 2000. "Life Itself." In *Global Nature, Global Culture*, ed. S. Franklin, C. Lury and J. Stacey. London: Sage.
- Franzen, Jonathan. 2001. "My Father's Brain." *New Yorker*, September 10, 81–91.
- Giddens, Anthony. 1991. *Modernity and Self-Identity*. Stanford: Stanford University Press.
- Gillick, Muriel R. 2000. "Rethinking the Role of Tube Feeding in Patients with Advanced Dementia." *New England Journal of Medicine* 342:206–210.
- Goodwin, James S. 1981. "Geriatric Ideology: The Myth of the Myth of Senility." *Journal of the American Geriatrics Society* 39:627–631.
- Gray, G. W. 1941. "The Mystery of Aging." *Harper's Magazine* 182:283.
- Gubrium, Jaber F. 1986. *Oldtimers and Alzheimer's: The Descriptive Organization of Senility*. Greenwich, Conn.: JAI Press.
- Haber, Carole. 1984. "From Senescence to Senility: The Transformation of Senile Old Age in the Nineteenth Century." *International Journal of Aging and Human Development* 19:41–45.
- Herskovits, Elizabeth. 1995. "Struggling over Subjectivity: Debates about the 'Self' and Alzheimer's Disease." *Medical Anthropology Quarterly* 9:146–164.
- Holstein, Martha. 1997. "Alzheimer's Disease and Senile Dementia, 1885–1920: An Interpretive History of Disease Negotiation." *Journal of Aging Studies* 11:1–13.
- Katz, Stephen. 1996. *Disciplining Old Age*. Charlottesville: University Press of Virginia.
- Kaufman, Sharon. 2000. "In the Shadow of 'Death with Dignity': Medicine and Cultural Quandaries of the Vegetative State." *American Anthropologist* 102:69–83.
- Morrison, S. R. and A. L. Siu. 2000. "Survival in End-Stage Dementia Following Acute Illness." *Journal of the American Medical Association* 284:47–52.
- Nascher, Ignaz L. 1914. *Geriatrics*. Philadelphia: P. Blakiston's Sons.
- Novas, Carols and Nikolas Rose. 2000. "Genetic Risk and the Birth of the Somatic Individual." *Economy and Society* 29:485–513.
- Rabinow, Paul. 1996. *Essays in the Anthropology of Reason*. Princeton: Princeton University Press.
- . 2000. "Epochs, Presents, Events." In *Living and Working with the New Medical Technologies*, ed. M. Lock, A. Young, and A. Cambrosio. Cambridge, U.K.: Cambridge University Press.
- Reisberg, Barry. 1999. "Retrogenesis: Clinical, Physiologic, and Pathologic Mechanisms of Brain Aging, Alzheimer's, and Other Dementing Processes." *European Archive of Psychiatry in Clinical Neurosciences* 249, Suppl. no. 3.
- Rose, Nikolas. 2001. "The Politics of Life Itself." *Theory, Culture and Society* 18:1–30.
- Shenk, David. 2001. *The Forgetting*. New York: Doubleday.
- Taylor, Charles. 1985. "The Person." In *The Category of the Person*, ed. Michael Carrithers, Steven Collins, and Steven Lukes. Cambridge, U.K.: Cambridge University Press.
- Von Dras, D., and H. T. Blumenthal. 1992. "Dementia of the Aged: Disease or Atypical Accelerated Aging?" *Journal of the American Geriatrics Society* 40:285–294.