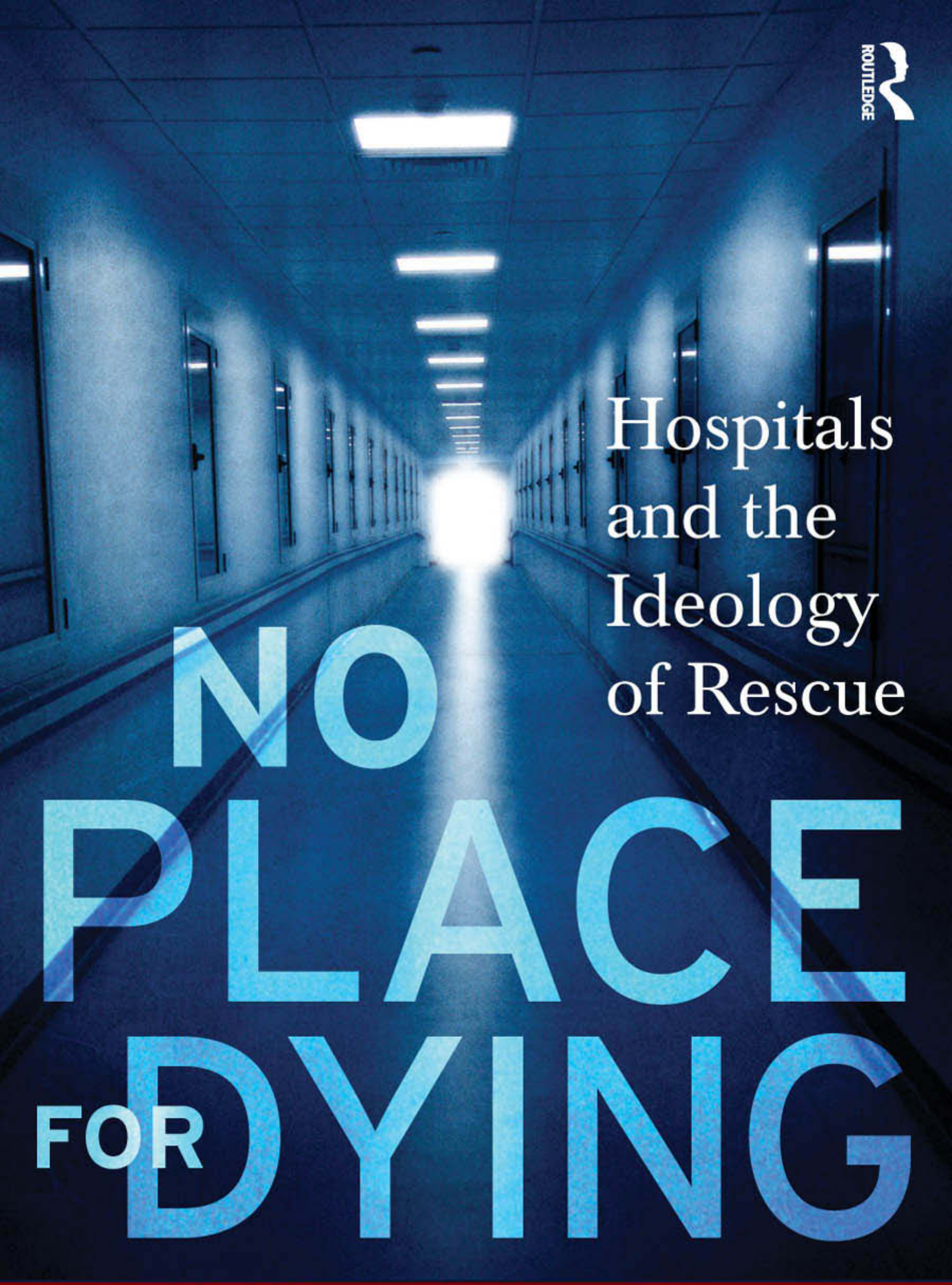

NO PLACE FOR DYING

Hospitals and the Ideology of Rescue

HELEN STANTON CHAPPLE

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Introduction

As a hospice volunteer more than two decades ago, I enjoyed sitting with dying patients. Family members could rest or run errands, leaving us alone together. Sometimes I did needlework at the bedside. Sometimes I fetched things or helped the patient to the bathroom. It was peaceful. The closer the patient was to death, the more I liked to be there. When I needed a new career, nursing seemed like a logical choice to extend my hospice interest.

Neither my early years as a stockbroker nor that volunteer experience prepared me for the shock of nursing itself. After nursing school, as I cared for cancer patients undergoing clinical trials, suffering with complications, or dying in the hospital, I wondered why so many people with terminal illnesses never went to hospice. Meanwhile, on the weekends that I spent as a hospice home care nurse, I was nostalgic for the old volunteering days. Now I was too busy advising family members and adjusting medications to sit quietly with patients.

Over the years, my question about hospice persisted and became more complex. To my surprise, hospital colleagues linked hospice to giving up, even to hastening death. One nurse distrusted hospice because she connected it with Jack Kevorkian—how prevalent was that misperception, I wondered? Clinicians projected themselves into the dying situations of their patients and expressed their own preferences for a quick death, not wanting to imagine family members surrounding *their* deathbeds. Physicians avoided predicting death as a prognostic outcome so that patients who died in the hospital were not recognized or treated as dying before death occurred. Hospice care at home was distant, hidden away, out of the mainstream of health-care delivery, so how could its elaborate benefits be real to clinicians who never worked outside the hospital? Some patients with terminal cancer preferred to enter Phase 1 clinical trials that offered no personal benefit, hoping that the data from their experience would help others, but their consent processes did not include a description of hospice as an alternative path.

I began a study of bioethics, thinking that the answers I sought lay in the process of decision-making around the end of life. To get closer to the dilemmas of choice, I steered my nursing career into critical care. Meanwhile, bioethics studies left many questions unanswered. They did not probe deeply enough into the profound struggles I witnessed between clinicians and families who sought the "right" way to treat patients, even as they focused on every aspect of the all-important (it seemed) decision to forgo treatment. Bioethics discourses were not riveted by the troubling situation of the dying patient in the hospital without hospice, as I was. Outside of the controversy about administering pain medication according to the Rule of Double Effect (Sulmasy and Pellegrino 1999), the care of patients who were actually dying in the hospital did not seem to disturb the world of bioethics. What were the situations of these patients, unacknowledged by the system that held them? What was happening to them as they were dying? How had they become so lost, to hospice and to everyone else?

It was an anthropologist's criticism of the limitations of bioethics' cognitive approach that introduced me to a new set of questions. Exploring anthropology allowed me to see that being "in the field" was an appropriate description of my stance in hospital nursing, one of almost continuous questioning. Here was a discipline that explored how groups make meaning out of the world around them and transmit that meaning to one another. While asking "How did *this* come to be, right now, in exactly this way and no other?" anthropology turns over the rocks in the path to discover what is hidden underneath. The medical side of anthropology uses these questions and techniques to explore healing practices and their implications for the groups who engage in them. This lens enabled me to explore how dying occurs in the U.S. hospital, paying particular attention to the experiences and actions of clinicians. I have found that they practice according to a cultural expectation of rescue that has particular implications for the persons who happen to be dying among them. This book explores hospital practices around dying and how they came to be.

Rescue and the Hospice Ghetto

The hospice patients I had enjoyed sitting with as a volunteer had already been placed in the dying category. There was little question about this, even from the patients themselves. Open awareness reigned, ensuring that the patients' lack of a future exempted them from public concern (Glaser and

Strauss 1965). The line had been drawn. To be in hospice was and is to be bracketed out of public participation and public awareness. At the same time, to be in hospice (or in a hospital's palliative care unit) is to be refuged and supported in a space where experts seek to meet specialized needs. Hospice and palliative care units in hospitals provide safe passage for the patients seen as dying, on the one hand, and protection for the public from "cross- contamination," on the other. My hospice colleagues observed wryly that local oncologists seldom referred patients to hospice until they were too weak to come to the office, an example of how such patients have dropped away from the legitimacy of social exchange (Baudrillard 1976).

Thus, a tension exists between safe places that support a dying situation such as hospice and palliative care and the wider social invisibility and dismissal that adheres to these places. The characterization of this seclusion as "privacy" may suit most patients and families perfectly well. But to leave it there leaves several questions unanswered: (1) How does this line-drawing between public and private, and between rescuable and dying, occur? Who decides which persons with serious illness are really dying, and by what criteria? (2) Why must such lines be drawn? How does the culture of the United States both benefit from and reinforce such removal of the dying experience? (3) How might the answers to these questions help illuminate the marginalization of the hospice experience?

Based on both my research and my clinical experience, I locate the hospice question in the U.S. interest in rescue. Rescue has become the gold standard for the delivery of acute care in the United States, and this priority profoundly affects dying situations that occur in the hospital. The quest for more time alive provides the market for the worthiest of commodities. Howard Brody's "rescue imperative" (1992: 91) and its corollary of stabilizing patients frame the care of U.S.'s dying patients, both inside and outside of hospice. To bring rescue to the forefront in this discussion rearranges familiar health-care categories.

When seriously ill patients in hospitals who are not recovering are determined to be "officially" dying, they are demoted from a first-class, rescuable status to a second-class, unrescuable status. Although dressed in clinical, scientific language, and thus supposedly an objective determination, this critical transformation is accomplished through practices in the hospital that I describe as a "ritual of intensification." Examining these ritual behaviors brings dying patients out of the "ghetto" of hospice and terminal illness and returns their problems squarely back to the land of the living. Making this line-drawing exercise that relegates dying patients to second-class status visible and challenging also allows us to reimagine its outcome.

The rescue imperative that characterizes U.S. hospitals did not emerge in a vacuum or out of positivistic scientific imperatives. Anthropology offers a lens through which we can see hospitals as institutions that evolved with specific social histories. Three strands of U.S. culture are particularly relevant to the argument of this book: ideologies involving technology, individualism, equality, and heroism; the growing instability of the concept of death itself; and the pivotal role that hospital clinicians play in drawing lines.

U.S. Ideology

Americans are enamored with drama and technological display and with the idea of triumph over adversity, dependence, and vulnerability. The popularity of body trauma television programs is a symptom of public fascination with the quick reversal of bodily misfortune through technology (Jacobs 2003). A fraught term in the social sciences[1], ideology is a useful concept with which to analyze life and death in U.S. hospitals because it rationalizes the striving toward socially acceptable goals, connecting moral understandings and representations of hope with politics. It is also a classic concept for describing the way societies rationalize gradations in social rank (Timmermans and Berg 2003). The common presumption that the United States is a single-class society is part of an ideology that blurs class and other distinctions and binds nationalism, positivism, and heroism with technology. Ideologies are often broadly shared among groups, but they serve the interests of an elite; they maintain the status quo while claiming to represent the world "as it really is."[2] This book shows how, in U.S. hospitals, prevailing concepts of egalitarianism and rescue disguise the distinction between first- and second-class patients and how those distinctions are made. The positivist ideology that technology and medicine represent operates with a view that the world "as it really is" justifies the drawing of class lines.

Critics may view technological progress in medicine as a double-edged sword, but patients and their families are almost always true believers (Eisenberg 1996: 163; Jacobs 2003). Rescue from calamity fits neatly with an ideology of overcoming adversity. In his classic treatment of death denial, Ernest Becker asserts that "society itself is a codified hero system, which means that society everywhere is a living myth of the significance of human life, a defiant creation of meaning" (1973: 7, 58). Although Becker's claim is perhaps hyperbolic in scope, it underscores the U.S. enthusiasm for heroism and triumph, indicating that both individual and societal success will depend on how well death can be denied.

These values have been a prominent part of national identity over the U.S.'s short history. Victories over the wilderness, outer space, and bodily limits in sports are seen as emblematic of the country itself. According to exceptionalists such as Seymour Lipset, binding heroism to national identity is unusually important in the United States. Because ideology rather than a common history brought the country into being, U.S.'s ideology sets it apart: "Americans are utopian moralists who press hard to institutionalize virtue, to destroy evil people, and to eliminate wicked institutions and practices. They tend to view social and political dramas as morality plays, as battles between God and the devil, so that compromise is virtually unthinkable" (Lipset 1991: 22).

The battle against death is the ultimate morality play. Even in U.S. funeral customs, to embalm and display the corpse as sleeping peacefully emphasizes the illusion of a "proper, fulfilled life" rather than the reality of death and putrescence (Metcalf and Huntington 1991: 210).

The instrumentation of medicine in flashy technology has particular meaning for U.S. society and its interest in overcoming rather than submitting to the inevitable. The fact that the health-care system costs more but obtains poorer outcomes than other industrialized countries is well documented, and some policy analysts such as Thomas Bodenheimer believe that technology accounts for a disproportionate share in these costs (2005: Part 2; California HealthCare Foundation 2006; Reinhardt, Hussey, and Anderson 2004). Such sobering international comparisons continue to travel under the public radar, while the media concentrates on stories of individual victories over calamity, dependence, and death. To reinforce the connections between technology and overcoming is to fortify salvational yearnings (Comaroff 1984; Good 1994). The willingness to be taken in by technology's dazzle is more robust for Americans than for Europeans, for example (Nye 2001: 104).[3] Publicity regarding medical breakthroughs now saturates the news media, reinforcing the idea that quality in health-care is directly related to the amount of technology applied. Dying patients who are nonrescuable share their less-compelling status with other patients whose maladies—mental illness, disability, chronic illness—are not amenable to instrumentation.

This culture of heroism and rescue is based in individualism. Because crisis readiness is prioritized, it appears that the medical system is designed to respond to every (otherwise self-reliant, unfettered) individual (Gordon 1988: 36). Such an idea of individual freedom cannot exert cultural dominance, however, unless it is equally available to all persons (Bauman 1992: 112). Anyone can call 911 and expect a response. But rescue, both as a figurative ideal and an embodied network, actually helps maintain the unequal health-care system. The universality of intent, perceived to be at the foundation of emergency rescue policies, stands in stark contrast to the widely documented disparities in overall U.S. health-care (Agency for Healthcare Research and Quality 2008; Becker 2004). Likewise, even if clinicians believe that they provide equal treatment at the bedside, perceived equality at that particular place does not address the social structures that both make people sick and present insurmountable obstacles to obtaining quality medical attention promptly (Farmer 2005; Zussman 1992: 40).

Self-reliance is a core U.S. value; pervasive fear of its opposite—dependence—proves the rule (Hsu 1972: 248). This attitude might explain the distaste for and invisibility of regarding routine care-giving in the United States described by Peter Lawler:

> We [Americans] think all human beings have an equal right to work and no right not to work. And we think that to be free means not to be dependent on others or constrained by them. We are against all forms of servitude and dependence, and we often see no real difference between paternalism and despotism. . . . Our goal is not to care for those who are suffering and dying—to help us live well with our natural disabilities—but to work hard to reduce and eventually eliminate the amount of suffering and dying in the world. (2004: 1)

Lawler implies that providing good care and saving lives are mutually exclusive, and so they have become in terms of national priorities. Rescue allows society to perform heroic acts that intrude on one individual at a time, and then only in case of catastrophe. Chapter 2 describes the development and implementation of rescue and individualism in U.S. medicine.

Universal Rescue Destabilizes Death

When the newly dead can sometimes be quickened by chest compressions and early defibrillation, death and dying are destabilized. Insofar as cardiopulmonary resuscitation (CPR) stands in for universal health-care in the United States and hospitals take their response readiness seriously, human finitude itself can appear to fade. By effectively omitting death as a foregone conclusion, rescue and stabilization strengthen the hero project that Ernest Becker identified as central to death-denying normalcy in the United States. But if natural physiological limits can occasionally be overcome, then restrictions on the use of rescue must also be found and justified. A new requirement has arisen with U.S. technological prowess and its universal application under rescue circumstances: the invention of a cultural exercise in line-drawing, a ritual for separating the living and rescuable from the dying and unrescuable, the first class from the second class.

Rescue efforts in the United States receive open, continuous support from technology, economics, cultural ideology, and the hope for salvation. By contrast, dying is poorly defined and happens in the shadows (see Chapter 3). To be admitted into hospice and receive its benefits, patients must relinquish a measure of social legitimacy in the (nonhospice) world they know, the one that privileges rescue. For these reasons, persons in the United States should not expect to receive both full attention to every physical threat to survival *along with* provisions for a comfortable dying situation when the time comes. These options do not carry equal weight, making the line-drawing much more difficult than is generally known. Further, to express or elicit these preferences through an advance directive or in some other form assumes a level of control and orderliness that may not travel in the same company with serious illness and death. It is up to the clinicians in charge, with their power as society's representatives, to mediate these differently weighted values at the hospital bedside.

Clinicians as Culture Bearers of Rescue and Comfortable Dying

My research in two U.S. hospitals examined practices around dying, situated in the environment of rescue as a social and ideological mandate. As sociologist Daniel Chambliss (1996) points out, patients and families in hospitals wrestle with issues vitally important to the shapes of their lives, including life itself. For clinicians, these struggles and the compassion they bring to them are simply what they encounter as a part of coming to work each day. How do the workplace routines and priorities inflict themselves on such life crises, and vice versa?

Nearly everyone in a hospital has brought the national culture and ideology of the United States into the hospital with him or her. The hospital is not a world unto itself but a part of the social "mainland." Meanwhile, each clinician reflects the particular culture of the hospital and even the unit where he or she practices, so that an iterative process occurs between the culture of the hospital and that of the society (van der Geest and Finkler 2004: 1998). But which society? The "mainland" understandings of technological care, best practices, and the social contract must be mediated through each hospital's corporate territory. In this book, I explore the role of the hospital as mediator between the macro and micro worlds of U.S. society, its economics, and bedside care. Meanwhile, clinicians at each site must be the action agents and the interpreters of the unfolding events in these life and death dramas. Clinicians are, then, unique as ritual agents displaying the particularity of the hospital subculture while also representing society as a whole (Singer 1989: 1193). Hospital practices are supposed to be evidence based and scientific, but they are also based on beliefs: a belief that health is the worthiest of goals; a belief that the consequences for wrong science, wrong belief, or wrong behavior are life threatening; and the practice and belief that "right science" can correct or ameliorate the consequences. The arena of the patient encounter becomes a "combat zone of disputes over power and over definitions of illness" (Taussig 1980: 9).

More specifically, clinicians represent public social attitudes, even as they, specialists in the domain of acute care, hold themselves apart. They (we) recognize that patients and families are naive when they believe that having "everything done" is almost always the best choice to protect their loved ones. If we foresee death as the outcome, we want orderliness in patient dying, so that the patient can be free of suffering, with loved ones close by, and with enough time to prepare so the death is peaceful and goodbyes can be said (see Chapter 3). We feel regret when the desire for "everything"—all the rescue that the hospital has to offer—crowds out the opportunity for peace and dignity around the death that we foresee as inevitable. We are often not aware that no other scenario may be possible and even less cognizant about why this may be so.

U.S. bioethics with its traditional emphasis on patient autonomy as the *sine qua non* of line drawing does not often address the multiple, hidden influences on agency, even as it has outlined the circumstances that permit the line drawing to occur in the treatment of seriously ill patients. In framing these issues anthropologically, I am able to describe and make explicit some of the forces that have been previously unavailable in the discourse.

Hospitals as Field Sites

I conducted ethnographic research in two hospitals in which I had never worked: a Catholic community hospital and a teaching hospital, both in a midsized city in the United States. I used a retrospective approach to interview clinicians about patients who had died. Before launching the major study, I conducted a pilot study in the hospital where I was working as an intensive care unit (ICU) nurse. For this preliminary work, the institutional review board (IRB) approved a method that allowed a member of the Decedent Affairs Office (DAO) to notify me every week as to where deaths had occurred. I could then seek interviews with the clinicians who had cared for the patients promptly after the death, even though I was not allowed to know patient names or numbers.

This process worked less smoothly in my subsequent research, partly because of my outsider status. (See the Appendix for further details of the ethnographic method.) Physicians were far less accessible in the fieldwork sites than during the pilot. In the teaching hospital, I visited the DAO every few days to obtain a new list of places and times where deaths had occurred. I would then visit the units and ask to speak to the nurse who had cared for a patient who had died there on a specific date. Without the patient's name, unit secretaries had to track down this information through their particular log books and records of patient assignments, shift schedules, and events. People were sometimes too busy to help with this. This exercise of unit detective work was the same in the Catholic community hospital units, but no DAO existed there to provide a list of recent deaths. It was several months before I cobbled together a reliable method to gather this information (see Chapter 2 for more details about this venture).

The fieldwork spanned sixteen months in 2003 and 2004. During this period I also worked weekends as a nurse in a third hospital nearby. In April 2003, new Health Insurance Portability and Accountability Act (HIPAA) regulations were enacted, further restricting access to patient information in U.S. hospitals. After obtaining IRB approval, I approached unit managers in group meetings and individually to obtain permission to be present on the units and to interact with their clinicians. Interview participants signed informed consent forms. Even with these protections in place, unit managers could, and some did, disallow my presence.

In the Catholic community hospital, my base of operation was the chaplains' group office, a large, carpeted room off the hospital lobby with desks and computers along two walls. In the teaching hospital, the too-small staff lounge in the palliative care unit was my home between interviews. Generally, I spent weekday mornings at one hospital site and afternoons at the other. I also attended gatherings on and off each site whenever the opportunity arose: in-service activities, training, commemorations, retreats, and meetings involving staff, bereavement, ethics, policy, and planning.

Through clinician narratives about their encounters with dying throughout the two hospitals and the pilot study, I heard about 211 patients of all ages and how they died. I used verbatim hand-written notes to record the interviews. I learned how nurses and chaplains, especially, along with a few physicians, respiratory therapists, and other providers viewed particular kinds of dying. Observations, meetings, and interviews with clinicians and administrators enabled me to trace variations in dying to differences in the corporate structures and management styles of the two hospitals as well as to the overarching cultural pressures they shared.

The community hospital was part of a Catholic hospital system with sister facilities elsewhere in the city and the country. The teaching hospital (also nonprofit) was an independent entity unto itself, academically connected to a state university. A third group of several for-profit hospitals competed in the metropolitan area along with the Catholic system and the teaching hospital. Each institution was exquisitely aware of the area's health-care market and its own fragile position within it. In a 1997 statewide comparison of hospital charges per case, the for-profit hospital system's charges exceeded those of the two nonprofit fieldwork sites in all thirty-five categories.[4] Operating margins for the nonprofits seemed razor thin by contrast, and their obligation to be stewards both of the community and of their own survival pulled them in opposite directions (see Chapter 5).

Arc of the Argument

Chapter 1 describes the difficulty of dying in an environment where rescue is the dominant mode of operation. It introduces five patients and the variety of dying situations that they encountered in both hospitals. The clinicians who cared for these patients used compassion, experience, and unit norms for guidance rather than established standards of care, because such standards were either not available or not useful. They experienced conflicting loyalties in carrying out this care. In an environment of rescue and stabilization, dying is a slippery category to delineate and retain.

Chapter 2 is about the rise of rescue and stabilization as the central organizing principle of patient management in U.S. hospitals. Through a series of shifts in health-care, stability has emerged as a ranking device in medicine, hospital triage, and in business, functioning as the bottom line for both profit and human finitude. With rescue as the gold standard of the delivery of acute health-care, heroism, speed, and good business can come together to reinforce each other as "democratizing": individualized, specialized care is offered to anyone demonstrating a need for it by their collapse. Stability and rescue become a vital bridge between the values of rationality and the yearning for recovery, on the one hand, and the productive engine of the health-care industry, on the other. Their respective power is built on the intersection of these beliefs, each of which is true to some extent, just as CPR is occasionally successful.

Having established rescue's primacy, it is important to understand how it interacts with the phenomenon of death in the United States, seen as accidental or coming at the end of contingency. Through rescue operations establishing machines as adjuncts to vital body functions, time can be manipulated. More time alive is produced; further contingencies can be explored; and the disorder of accident can be corrected. These efforts, which I call the ritual of intensification, offer the hope of not dying while maintaining social legitimacy. Such intense pursuit of any options other than death effectively distracts Americans from having to gaze into the abyss either individually or as a society, thereby aiding the hero project. If death results from the failure of rescue, it becomes a technical problem rather than an existential one. These developments have expanded the cultural distance that patients, families, and clinicians in the hospital must travel between "heroic" efforts for a patient with a future at one end of the spectrum, and an assessment of "dying" on the other. The ritual of intensification is the map that clinicians use to find their way through this territory. I show how this works by narrating the process as it played out in three patient examples.

Counter-discourses of bioethics and the revival of the death movement (hospice and palliative care) have risen up alongside rescue's dominance, but they sometimes enhance rather than mitigate dying's marginalization. Bioethics gives permission for the suspension of the ritual of intensification under certain circumstances, and the "revival of death movement"—so named by Tony Walter (1994)—defines an alternative space for the dying patient through palliative care or hospice. Neither bioethics nor hospice challenges the dominance of rescue, and both could be said to be necessary to it—providing relief valves for its unremitting tension and allowing it to continue to define the shape of routine medical care in the hospital.

But then how does death actually occur in the hospital? Because death is not out of the question in acute-care settings, its containment is highly developed. Rescue and stabilization efforts enable an interval of dying to be demarcated, separate from mainstream care, and clinicians in both hospitals can take steps to minimize its impact. Because death can occur, it should happen with as little dying as possible, as an anticlimax, properly domesticated, in contrast to the chaos of treating serious illness. The dying situation seems to be a greater threat in the hospital than death itself, and it cannot be recognized without proper sanction. In Chapter 4, I show that "right" dying happens in the expected times and places, progressing in a linear fashion, without chaos and with consensus. "Wrong" dying is out of order, time, and place, and not properly contained. These general patterns of dying and the attitudes clinicians expressed are significant because of the level of control they often exert in the situation, enabled by their skills in stabilization.

The striving for triumph over calamity, especially death, forms the background not only of rescue, but through these efforts it also fuels big business in the United States. The connections are appropriately mystified and cloaked within the hospital so as to be virtually unidentifiable (and unimpeachable) at the bedside. These forces have their own agendas, hidden from the participants but operating on them nonetheless, and almost impossible to resist because of the lure of more time alive. If death is the ultimate human problem, and if individual rescue represents the promise of overcoming, it is not surprising that escaping crisis is prized in the economics of health-care. Productivity and rescue are jointly beneficial to industry within and beyond the hospital because both emphasize speed of action. The economics of rescue are not divorced from the culture and the ideology at large, but are a product of it.

"Every medical action is a transaction," (Middleton 2004) but in the hospital where lives are at stake, the monetary values must be kept separate and obfuscated during the process of exchange in favor of medicine's broader significance to the culture. In Chapter 5 we explore this process. Americans must believe in medicine and its practitioners as pure, untouched by the toxic influences of economic gain, especially at these moments of extreme vulnerability. The hospital's technology is dazzling and stamps the individual receiving it as valuable and legitimate. The immeasurable value of life-saving is matched by the unfathomable mystery of its instruments. Meanwhile, elaborate coding vocabularies ensure that it is both quantifiable and reimbursable. No coding slot exists for palliative care, however, so dying has no grounding in the economic infrastructure. This process of values mystification lays the foundation for the discussion of trust in Chapter 8.

In Chapter 6, I describe how the connection between the hospital and the industry of rescue influences the care of dying patients. The issue of overcrowding in the emergency department (ED) and the diversion of ambulances to other hospitals is a window onto the issues of cost and throughput (a measurement of production over time—i.e., how efficiently patients can be treated and discharged) faced by U.S. hospitals. The resulting pressure affects care of dying patients in ways that are peculiar to each site's culture. In the Catholic community hospital, after the patient's rescuability is ruled out, it is easier to free up his ICU bed than it is to pin down his subsequent plan of care. One mixed unit of hospice and medical-surgical patients can accommodate any unrescuable patient without the need to specify goals of care. Clinicians here have no trouble extending open-ended intervals of time to patients who are dying. But in the teaching hospital's environments of intense rescue, the tolerance for waiting is low. Clinicians voice preferences for short, predictable dying situations, along with their fears that families will second-guess the decision to withdraw life support if death does not follow promptly. Dying is conflated with suffering, and no value apart from limiting suffering seems important once consensus about the dying has been reached. Finding it difficult to tolerate feelings of helplessness, these clinicians see themselves as being held hostage to the dying situation rather than deriving a sense of honor or privilege in being close to it, as is more common in hospice or palliative care.

In Chapter 7, I shift focus from the patient's dying situation back to the ritual of intensification, which comes in for closer scrutiny here than in Chapter 2. It is the crucial mechanism of transformation from living to dying, and I consider its general program along with the factors of practice that could lengthen or shorten it. The ritual creates order out of the chaos of serious illness for clinicians, according to the priorities and instrumentation required by rescue and stabilization. It provides the goals for the patient's clinical course and the shape for its narrative, along with a formula to resolve the uncertainty of his fate. True to form, this ritual enacts the transformation of the rescuable patient to an unrescuable status, and its practitioners often contest its operations among themselves. But rather than ending by reintegrating the patient into the social body as most rites of passage do, this ritual enables her to be cast off from it, while avoiding social guilt and without threatening the project of medicine itself. The ritual's "tipping point" of clinical decision and the testing of that conclusion with the family prove the success or failure of the ritual. At this juncture, the patient's deterioration toward death is explicitly declared to be not a crisis, not eligible for rescue interventions. It appears that this one-by-one reclassification of seriously ill situations into dying situations has become the extent of the American encounter with death.

The ritual enables clinicians who have been inflicting suffering in the name of life-saving to make up for it at the end by the intensity of the compassion they display in relieving the patient's dying. Not surprisingly, the ritual of intensification differs in the two study hospitals. Fewer ICU beds in the Catholic community hospital and the absence of interns and residents enable private-practice clinicians and nurses to take actions that are more arbitrary and less patterned than in the teaching hospital, where individuals have less personal power.

In Chapter 8, we consider the issue of trust in the U.S. health-care system. The elaborate rescue endeavor can be seen as a ritual display; an active demonstration of technology in crisis can be seen as an effort to compensate for the system's widespread shortcomings in providing basic care. The ritual of intensification seeks to establish trust, so that when clinicians impose care limits to avoid "futile" resuscitation attempts, families and patients will assent. The display of rescue perpetuates the differential in power between clinicians and patients while seeking to win their loyalty to it.

As palliative care programs have gained favor in hospitals, clinicians have a consolation prize to offer to patients and families when they want to close down the ritual of intensification. I investigate the trustworthiness of this option as it existed in both hospitals and explore its compromised position in the U.S. hospital and in the health-care system. If hospitals are urged to use palliative care to offload their expensive ICU beds, what message does this convey about the intrinsic worth of dying patients? I propose that neither the ritual of intensification nor palliative care can be ultimately trustworthy as guardians of the dying, because both represent a health-care system housed within a cultural system that cannot accommodate the experience of dying in a value system of self-reliance, individualism, and heroism.

What might be done? How can hospitals make a place for hospital dying to occur without it being subject to diminishment? To expect the dying patient herself to insist on her rights is not the answer. Looking again at the ritual of intensification, we find that instead of leading toward social incorporation in the normal way of a rite of passage, it works in the opposite direction, as a mechanism of isolation. As we consider how to reverse this process and incorporate dying persons into a legitimate social space, the variety of dying scenarios that occurred in the two research sites offers a glimpse into the daunting complexity of the issue. In conclusion, I invite a thought experiment with the concepts of recognition and witness as avenues for movement in a different direction.

The New American Morality Play: Becoming More Human

One chaplain told me that she derived no energy from the dying patient in the bed, in contrast to my own experiences sitting with hospice patients. "The heavens don't open," she said. It is common for hospital clinicians to express a preference for their own death to be swift and painless. During my time in the field, a friend in health-care challenged me to describe what I wanted to see happen for dying patients. If the patient is at death's door, why would one advocate for them to be allowed to die in their own time? What would be the reason, other than simple romanticism, to want to open up that space?

The answer is in three parts, and it comes from my experience at the bedside, anthropological inquiry, and existential reflection. As a long-time critical-care clinician, I am steeped in the culture of rescue, of death prevention. As long as the patient is comfortable by any measure that an outsider can judge, he should be allowed to take his own time, to define his own dying. To take steps that could invite death in is to side with the enemy. Further, it implies a lack of courage to share in the patient's powerlessness as we wait for death's approach. My willingness to wait is an act of defiance. Now that the end is at hand, death should not have it too easy.

Moving into a different metaphor, to abort the journey would be to refuse to learn from my patient's experience, or even to be in his company. It would also show disrespect for this voyage we have in common. Not to hasten death, but allow it to take its time means that I am open to the human condition that we share. I have no desire to add to his distress, but to allow the journey to be exactly what it will, as long as detectable suffering on his part is not an issue.

Finally, I believe that to characterize the dying situation as a generative process rather than an anticlimax or a foregone conclusion is a way to enhance our own humanity. David Hilfiker points out that to marginalize others is to become alienated from oneself (2005). In our zeal as clinicians to prove our compassion and wipe out suffering through large doses of opioids and sedation after life-support technology is gone, we are treating the dying patient as if he were, if not dead already, then as good as dead. It is too easy in the United States to dismiss the dying person, to put him out of *our* misery. In my role as a representative of society, as a party to the social contract, I want society not to do this. Further, persons who are dying present vulnerability and finitude to Americans more completely than any other marginalized group. Perhaps this is why they are so shunned. The title of the disability rights group "Not Dead Yet" indicates that they recognize an even greater marginalization than disability, aimed at those living persons socially defined by the imminence of their death. Even if the person herself loses her sense of personhood as the body deteriorates (Lawton 2000), selfhood can be ascribed and honored by those around her.

My objective in presenting this investigation and interpreting its findings is neither to arouse existentially appropriate despair over the human condition nor to call attention to Americans' pattern to diminish dying patients in the public space of the hospital. Nor is it only to represent the situation of hospital dying in an anthropological framework that may offer new insight. I submit an alternative conclusion, drawing from the insights of literary scholar Eugene August (1981) regarding endings and how they are judged. His points relate to the hero project in the United States and its denial of death and vulnerability in such a way that allows us to redefine our notions of heroism.

August draws a careful distinction between divine comedy in literature and the comedy of laughter, and he makes a case for removing the tragedy from its position as "the highest form of art" (1981: 86, 87). Divine comedies strike a tone of "high seriousness" and feature reconciliation with the gods or with a divine power at the end, after the hero has overcome his hubris and recognized his human limitations. "Starting with a mistaken notion of what it is to be godlike, tragic heroes often attempt to impose their will up on others in a way that denies their oneness with them; divine comic heroes modify pride as they discover what it is to be truly godlike, not by a denial of their humanity but by a perfecting of it" (p. 94).

These heroes' new awareness is not passive humility, but a quest to experience humanity more fully. I submit this road to heroism as an avenue to improving attention to the realm of the dying patient in the U.S. hospital, outlined with a few specifics in Chapter 9.

On a cultural level, one could imagine the elevation of the dying person to a place of honor, earned by having survived the ordeal of the ritual of intensification. The hospital could display this honor through a display of opulence in goods, services, and surroundings in the setting of excellent palliative care. Even if the patient is beyond awareness, such outlay would demonstrate his value as a pilgrim, an explorer of lands yet unknown to those still capable of an upright posture. An extravagant display of palliative care might inspire a consumer response. It could protect the patient from intrusion while providing persons ready to listen and record family stories, opportunities for gatherings, and invitations to ceremonies marking the importance to the culture (as well as the family) of this momentous event.[5] Barbara Adam reminds us that "Transcendence is always an immortality of the spirit which is constituted by our relationship to the temporality of life" (1995: 38).

Of course, it would not be for everyone. Vanstone (2004) indicates that perhaps a third of people might be interested in considering the "stature of waiting," as an alternative to exploring every contingency of more time alive. Satirist Art Buchwald was one of those people. He turned away from dialysis and chose, not death, but whatever might happen apart from his particular life-prolonging treatment. When he signed himself up for hospice care in February 2006, his death from kidney failure was expected imminently. The importance of his experience is not the remarkable eleven months that he lived after his decision, enjoying his status as a condemned but celebrated personage. No one could presume that such a boon would be part of the bargain.[6] Instead, the significant point was that he had the courage to turn away from rescue and explore his own humanity, rather than to seek to be saved from it.

Notes

1. In their discussion of cognitive archeology, Kent Flannery and Joyce Marcus differentiate between cosmology, religion, ideology, and iconography. See Flannery and Marcus (1993: 263).
2. Andrew Levine defines ideology as "a body of doctrine, more or less comprehensive, that, deliberately or not, systematically serves particular interest at the same time that it purports to represent the world as it really is." See Levine (2004: 6).
3. Nye sees this interest in technology as spanning ethnicities in the United States, with the exception of "the Amish, many Native Americans, some of the rural poor, and some of those living in communes" (2001: 109).
4. This consumer-oriented health-care watchdog organization has not made a more recent comparison.
5. Lock (2002) describes hospital gatherings after patients' deaths in Japan that clinicians routinely attend.
6. Stephen Connor and his colleagues (2007) have shown that hospice patients can often live longer than patients with similar diagnoses who are not part of a hospice program.

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CHAPTER 1

Hospital Dying Situations

When hospital clinicians care for dying patients, they are often on their own, practicing with few or no specific guidelines in a way that typifies virtually no other hospital clinical practice. The move toward standardizing most of the care of patients in hospitals has deep roots. Near the beginning of the twentieth century, hospitals in the United States insisted that all patients have standardized medical records. One consequence of this standardization was that patients perceived to be from lower classes (people of color, immigrants, the poor and indigent) benefited from this more democratic treatment. Physicians treating well-to-do patients had to open their private notebooks, so that patient care methods used for the wealthy and powerful became accessible to clinicians and accountants (Timmermans and Berg 2003).

Using the critical task of documentation to manifest both equal opportunity and presumed transparency helped make it possible for U.S. hospitals to become demonstration projects for societal ideals. Medicine was a social good, and medical records, as tools of research, reimbursement, communication, and accountability, could advance that good. Standardization promoted goals of both science and efficiency in hospitals; it could reinforce the expectation that scientific advancement could be translated into ever improving health-care quality.

These progressive ideals, even elaborated and contested over time, have remained alive and well in the U.S. hospital. Quality improvement efforts, policies that make cardiopulmonary resuscitation the default for every hospitalized patient, and the movement toward evidence-based medicine are all grounded in the belief that practice should be guided by and informed by standards. Every life-saving intervention practiced in hospitals has a protocol to guide its proper implementation. Clinicians proclaim their belief that practice must be guided by what is best for the patient, therefore general standards must be modifiable based on individual cases. Still, the standards are the starting place; they are what stamps health-care practice as legitimate and professional.

Delivering health-care according to set standards has served hospitals well as the means for holding back death have become ever more elaborate. Because compliance to practice protocols pervades clinical practice in U.S. hospitals, standards can serve as useful lenses to begin exploring how dying occurs there. Hospitals produce more time alive as their most valued commodity, and mortality rates are one measure of their success. If the hospitalized patient is officially recognized as dying, however, he is no longer a candidate for life-saving. To be disqualified from rescue may place the patient not only beyond the reach of that paradigm but also beyond the standards themselves.[1] Further, because rescue care is much more closely tied to reimbursement than nonrescue care (see Chapter 5), care for patients who are dying may be documented less rigorously and is rarely subject to review. What might this change in status mean for the patient, and how does it come to be?

Implications for dying and "Dying"

Subsequent chapters answer this question by examining the development of hospitals as both culture and industry. In this chapter, I explore what the dominant standard of rescue and the experience of being disqualified from rescue mean for the dying patient. First, I show that in the U.S. hospital, Dying patients who are officially recognized as such (thus written with a capital D) and are not under hospice or palliative care almost always occupy a devalued social position compared to non-Dying patients. Because acute care in the United States is thought to be an egalitarian endeavor with standards of excellence applicable to every patient, to move a patient beyond the reach of those standards, to label the patient as officially Dying, is an act of delegimization. Changing the patient's code status from "full code" (the default mode and often simply assumed) to "no code" or "Do Not Resuscitate" (DNR) (which requires clear articulation) is an example of this practice. As such, it requires ritual behavior to exonerate it, as we shall see. Once delegitimization has been accomplished, the patient and her caregivers are often completely at sea. To extend the analogy, uncontrolled wetness itself is an anathema (as every clinician knows), a signal of insidious disorder. The journey that had been clinically mapped toward stability and cure is now adrift, buffeted by circumstance, pulled under by hospital currents, navigated by arbitrary preference, and often beyond the reach of tracking, accountability, standardization, and quality. Most persons want to get back on dry land as soon as possible, to feel sure-footed and in control.

To become acquainted with the diverse dying situations occurring in hospitals is to discover dying to be a very slippery category, difficult to grasp. (I prefer the term "situation" to "process" because it gathers in persons beyond the central individual and because what is happening may not be at all linear or orderly [Kastenbaum 1978].) The persons who populate dying situations slide in and out of the hospital's focus, which is fixed on regulations, outcomes, and bottom lines. In the hospital, to be legitimate means being under the aegis of care standards, governed by some form of oversight or quality control. Because dying does not fit with the expectation of clinical spaces being devoted to improving health and saving lives, it is minimized when it occurs in those spaces, or it is swept beyond view into palliative care. The hospital reflects a broad-based consensus that dying (when clearly occurring) is supposed to be a private matter, properly left to families and not a matter of public or social concern. This attitude reflects the priorities of the larger society, and why would it not? The U.S. hospital embodies the most highly realized incarnation of the society's hopes for itself: a technological bastion standing between itself and death.

Just as every life is unique, every dying situation tells a story different from any other. The five situations of dying in this chapter fixed on the imaginary slide for our inspection serve as orientation to perplexities explored in later chapters. Mr. Diangelo[2] and Mrs. Harper, the first two cases, were patients in the Catholic community hospital. The next two patients, Mr. Gomez and Ms. Hunter, died in the teaching hospital.

Case One: Mr. Diangelo

Mr. Diangelo's longstanding lung problems made it surprising that he survived to see his 90s. He had been in and out of the hospital recently, and he was alert and responsive when he was admitted a week before. Details of his clinical course were not available, but during this admission a decision had been made to write a DNR (or "no code") order for him.[3]

During what would be the last weekend of his life, Mr. Diangelo was in a stepdown[4] unit so that his cardiac status could be monitored. On Saturday, his breathing became more labored, and the staff tried several interventions to assist him with varying success.

> RN: He was on 6 liters nasal cannula plus a fifty percent face tent, and when I went in to check him, he was not doing well. His sats were 50 percent[5]—I mean he was BLUE. It had happened before at midnight, and the face tent was added then. [Now] We went up to 75 percent face tent. That didn't do the job for him. So we paged respiratory and we talked about putting him on a nonbreather.[6] The fact was he was blue. We had to do something. The nonrebreather and the nasal cannula seemed to help. He did good with that through the day. Then Saturday later in the day he was in trouble again. The house doctor came up. The respiratory doctor was called. We put him on the BiPAP[7]—that worked. He seemed okay when the family was there.

Mr. Diangelo's requirements for oxygen and breathing support had moved from simple (nasal cannula alone) to just short of intubation[8] (BiPAP) over the space of a few hours. During that time he suffered several bouts of severe respiratory distress, and in each case the staff stepped up his oxygen support. This final step involved putting a mask over his nose and mouth arranged to create a very tight seal so that the machine's oxygen would go into his lungs without escaping out the sides. BiPAP is considered a temporary measure because of its discomfort, the patient's inability to eat or talk, and the dry mucous membranes it causes.

> RN: On Sunday he was more awake, pulling the BiPAP off, even talking some. The problem was, I had four patients. I could not sit at the bedside. So every time it got dislodged, his oxygen saturation dropped. The family requested wrist restraints. So we did that. Sunday afternoon he could dislocate the mask by turning his head or moving down in the bed. When he started pulling that BiPAP off Sunday afternoon, we were constantly in there. I called the admitting doctor and he wasn't on call. The covering doctor—they didn't know him. He said he would call the one who saw him Sunday morning. I asked the doctor, "Do you want to put him in the unit?" "No—he's a no code. They don't want to intubate," so that was it. He would order Dilaudid.[9] We were afraid it would wipe out his respiratory drive. But I gave him some before I left, and it did fine for him. He was able to rest and didn't fight the mask.
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> On Monday, the respiratory doctor came in. That's when they decided it was okay for him coming off the BiPAP. They were ready. They were prepared.

HC: That was three doctors?

RN: Four doctors in all.

Having benefited from improved oxygenation overnight, Mr. Diangelo was more alert on Sunday morning, more aware of the mask and its discomfort, making the BiPAP a double-edged sword. Recognizing that Mr. Diangelo's increasing struggle against the mask was an unsolvable management problem, the nurse suggested an alternative plan of care: that the physician write an order to move him into the ICU. Staffing issues alone are rarely enough to buy an ICU bed, and this physician immediately rejected this idea along with the unspoken option that would do the trick: the invasive procedure of intubation and mechanical ventilation. His reason, as reported by the nurse, is telling. Rather than pointing out that Mr. Diangelo's need for more and more oxygen indicated that he was dying, or that intubation would not solve the problem, the doctor cited Mr. Diangelo's status: he was a no code—he was no longer a candidate for rescue care. The nurse's response is also revealing: "so that was it."

Elaboration regarding other possible options for caring for Mr. Diangelo seemed unlikely. Mr. Diangelo's no code status itself seemed to be the extent of his plan of care, although I heard the maxim elsewhere in this hospital that "'no code' doesn't mean 'no care.'" Now the plan dictated that the nurses cope with Mr. Diangelo's struggles to remove the mask and the staff's attempts to replace it or restrain his movements. The order for the medication that allowed him to rest had come well into the second twenty-four hours of Mr. Diangelo's respiratory difficulty. This measure initially presented a problem for his nurse, who was reluctant to do it in case it compromised his breathing. In the end, he received it because she was willing to take a gamble that it would not kill him by "wiping out his respiratory drive."

None of the four physicians who consulted on Mr. Diangelo's respiratory difficulties over the weekend was his attending physician, because that person was not on call. Staff and physicians did the best they could to relieve each episode of Mr. Diangelo's distress in the moment. But without the attending physician, it was no one's specific responsibility to evaluate the adequacy of these measures, to draw conclusions, or to take action based on those conclusions. The nurse told me that she thought that Mr. Diangelo's repeated attempts to remove the mask were indications of his wish to die, but she did not have the authority to act on that assessment.

On Monday morning, when they were "ready" to remove the BiPAP and allow Mr. Diangelo to die, his next-day nurse related the events that followed.

> RN: The pulmonary specialist came in and saw him. He spoke with the family and said we were prolonging the inevitable. When the doctor said, "turn the BiPAP off," he said to keep the Dilaudid. He didn't seem like he was in any distress. We kept the BiPAP on till all the family came. So we waited a little bit before.

The phrase "prolonging the inevitable" is an official pronouncement. With it, the "dying" that the previous nurse recognized on Sunday through Mr. Diangelo's attempts to remove the mask became "Dying," that is, certified by the physician and by the family meeting. It was also a statement about both the immediate past and the immediate future. In hindsight, it summed up the experiences of the weekend, confirming the common belief that to be dying is certainly also to be suffering. Hadn't they all seen Mr. Diangelo suffering before he received the Dilaudid? "Prolonging the inevitable" also framed a dualistic choice about Mr. Diangelo's future that now seemed to face them: either use the BiPAP to continue to produce more time alive, or remove it and allow death to occur. Mr. Diangelo's state of Dying in the here and now invited no particular care plan in itself, no set of interventions tailored to this situation, other than simply to get out of death's way.

Still, the nurse did not follow the physician's order immediately, and I asked her about the fact that she "waited a little bit."

> HC: How did you know to wait for people to come in?

> RN: It was common sense. He did not say I had to take the BiPAP off at a certain time. The daughter said, "You don't have to wait." But I said, "Take whatever time you need." I've had dying grandparents. You need time.

Mr. Diangelo was not suffering at the present moment. Informed by a personal experience with her grandparents rather than by protocol, this nurse gently redirected the daughter and managed the situation with perhaps the only tool she had at her disposal: determining when the removal of the BiPAP should occur and doing so according to her internal rhythm of "common sense." Her delay to allow the family to gather and have "time" was a care plan that acknowledged the unique stature of dying, one that deserved such attention.

> HC: How did the death occur?
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> RN: We took him off the BiPAP. He did have nasal cannula. He expired in maybe thirty minutes after we cut the BiPAP off. We had him on the heart monitor and saw the heart rate go down. The daughter came out and asked me, "Could you check on him? I think he's passed." I listened to his chest and called the house doctor to ask his opinion. He came within five or ten minutes. The family stayed fifteen minutes after. The daughter seemed at peace. She said, "He was 92 years old, he had a good life. He shouldn't have to live this way." With the progression over the weekend, they had time to contemplate his passing and were okay with it.
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> HC: How did it go from your perspective?
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> RN: All in all it went well. The doctor said he didn't have much [respiratory] effort on his own.

The nurse's sensitivity about timing the BiPAP removal perhaps also explained her absence at the bedside. She may not have wanted to intrude, perhaps unaware that she had a valid role to play. If she had been present with Mr. Diangelo and his family, she could have assessed and interpreted the physiological changes that were surely occurring during the interval that passed between the removal of the BiPAP and his death. She did not join them in the room when the monitor outside signaled his imminent death, but waited for the family to emerge and inform her of his "passing." She followed the after-death protocol and called the physician for pronouncement. She perceived that everyone was satisfied with how events had unfolded, although Mr. Diangelo's opinion was not sought. Further time alive would seem to have brought only further suffering, and Mr. Diangelo's weakened frame had "proved" over the weekend that it could not generate respiratory effort. His death had been controlled, the family was "at peace" and did not overstay. For her, orderliness reigned: "it went well." The lack of respiratory effort "on his own" confirmed the rightness of the decision to stop trying to keep him alive.

Mr. Diangelo's respiratory status had been tenuous before the weekend, and the DNR order written soon after admission indicated that his attending physician anticipated a fatal deterioration at some point. The fact that he was still in a telemetry bed being monitored indicates some ambivalence about Mr. Diangelo's situation. By removing him from the category of rescuable, the DNR order had guaranteed what treatment he would *not* receive, but did not specify what clinicians should *do* in case his fragile stability gave way. When he went off duty Friday afternoon, the attending physician's instructions to the covering clinicians had omitted this detail. When Mr. Diangelo's needs changed, clinicians responded in the moment, according him increasing respiratory support but little relief. It was certainly simpler to manage his distress than to confirm openly the possibility that they were bearing witness to the final hours of his physical presence among them.

I did ask the weekend nurse what she might have changed about Mr. Diangelo's case, and her hindsight was more mixed than that of the nurse who cared for him the day he died.

> RN: Because he was a no code, I think he could have come off the monitor and gone to hospice. I don't know why that didn't happen.
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> HC: Would the attending have done that?
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> RN: I think so. Because it was the weekend and the on call doctors don't make those decisions, as you know. If the BiPAP could have been weaned off and gone back to face tent. But it became obvious that when he went on the BiPAP, he wasn't going to come off. Sometimes it works and sometimes it doesn't. But I'm comfortable with it. We did everything we could do, and it didn't work because it was in God's hands, not ours.

In hindsight, this nurse acknowledged that Mr. Diangelo's "obvious" dying (judging by his dependence on the BiPAP) could have become Dying, that is officially recognized, before Monday morning. She saw the possibility of finding a more substantive plan for Mr. Diangelo than simply getting out of death's way. Still, she comforted herself that she and others did not shrink from their responsibility to try to help him. In her narrative summation she used a bottom-line assessment: they had never abandoned him, and they could not save a life that God had chosen to take. She did not assess the quality of his care in terms of his being a dying patient for two reasons: Mr. Diangelo was not considered to be Dying until Monday morning, and the important outcome that merited attention in her mind was that he had died at all.

For Mr. Diangelo, the DNR order had not brought along a distinctive treatment plan, and the status of being unrescuable disqualified him from attention paid by an authority high enough to compose one. The staff's goal in the moment was simply to lessen his work of breathing. Certainly he was not left alone, but the care he received did not match his clinical situation. He occupied a bed, a portion of a nursing assignment, and the attention of four physicians, but his dying had no status at all. The system had no way