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# The Rhetoric of Hospitality: Conditions of Death in America

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THE RIGHT OF HOSPITALITY:  
CONDITIONS OF DEATH IN AMERICA

A Dissertation

Submitted to the Graduate Faculty of the  
Louisiana State University and  
Agricultural and Mechanical College  
in partial fulfillment of the  
requirements for the degree of  
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in

The Department of English

by  
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For Mom, Dad, and Brendan  
for teaching me to make the best of what's around

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## Abstract

*The Right of Hospitality: Conditions of Death in America* calls Western biomedicine's approach to death into question. Death unifies all human experiences and is always possible, despite the human tendency to deny its existence and, instead, orient the self towards a futurity that is always out of reach. This project investigates the structures influencing how death in America occurs, and traces the roots of Western culture's rejection of death to the execution by hemlock of Socrates' immortalized in the *Phaedo*. Western biomedicine's institutionalization of medicine requires that both patients and doctors enter into imbalanced hospitable relationships, and these pressures, along with the rejection of discourse about death, make for a difficult and dehumanizing end-of-life care system in America today. Case studies of contemporary experiences of death—including Oregon State's Death with Dignity Act, Brittany Maynard's end-of-life activism, and a patient's dissatisfaction at the extension of his life—provide opportunities for teasing out the ethical issues surrounding end-of-life. Ultimately, the options presented to patients at end-of-life are not simply a matter of hospitality; they are a human rights issue. This issue promises to dramatically alter the experiences of the world's rapidly growing number of humans kept alive by modern medicine, and if it is left uninvestigated, will force Americans into woefully insufficient end-of-life care.

## Chapter 1

### Introduction

In *When Breath Becomes Air*, neurosurgeon Paul Kalanithi writes: “What patients seek is not scientific knowledge that doctors hide but existential authenticity each person must find on their own. Getting too deeply into statistics is like trying to quench a thirst with salty water. The angst of facing mortality has no remedy in probability” (135). Kalanithi composed *When Breath Becomes Air* during the final year of his neurosurgical residency at Stanford University. He was 36 years old, and had just been diagnosed with terminal stage IV lung cancer. *When Breath Becomes Air* reads as a coming-to-terms with death, but even more so with his newfound, and identity-shattering, experience as a doctor turned patient. Kalanithi writes that, “While being trained as a physician and scientist had helped me process the data and accept the limits of what that data could reveal about my prognosis, it couldn’t help me as a patient. It didn’t tell [my wife] Lucy and me whether we should go ahead and have a child, or what it meant to nurture a new life while mine faded. Nor did it tell me whether to fight for my career, to reclaim the ambitions I had single-mindedly pursued for so long, but without the surety of the time to complete them” (139). For Kalanithi, these questions of prioritization are ones he finds himself incapable of answering on his own—he needs professional opinions in order to gauge his abilities—and “rebuild my old life—or find a new one” (139).

Kalanithi’s memoir reveals two key issues that this project hopes to illuminate and solve. First, there is a startling lack of discourse about illness and death in contemporary American culture. Kalanithi frequently comments on what this project will call the generic social response to illness, or the rhetoric of warfare that is pervasive in

contemporary medicine and treatment: a discourse in which the ill are encouraged to fight, told to be strong, and either implicitly or explicitly shamed for moments of weakness and hopelessness. In Kalanithi's memoir, even his brother, himself an accomplished physician, encourages him to maintain hope in the face of his incredibly aggressive terminal illness—to which Kalanithi “sighs,” and thinks that “He meant well, but the words rang hollow” (120). And this interaction brings us to the second knotty issue that this project hopes to begin untangling: even medical professionals, the self-proclaimed and culturally perceived experts on death and dying, find mortality (and, perhaps more succinctly, medicine's inability to conquer illness and death), a difficult pill to swallow. Kalanithi writes that, “Death, so familiar to me in my work, was now paying a personal visit. Here we were, finally face-to-face, and yet nothing about it seemed recognizable” (121). These two problems are basically one of language and one of comprehension; they act cyclically, and have prevented real progress towards developing a discourse about terminal illness and end-of-life. In reality, the contemporary experience of end-of-life is a complicated series of contradictions. Just one example: while a recent study by the Stanford School of Medicine found that approximately “80% of Americans would prefer to die at home, if possible” (“Where do Americans die?”), the study also found that despite this desire, “60% of Americans die in acute care hospitals, 20% in nursing homes, and only 20% die at home” (“Where do Americans die?”).

But few Americans understand the reality of these alternatives and how difficult access to services like hospice might become at end-of-life. Still fewer recognize the limited personal agency they will likely experience when they enter into the final phases of life—either from a “natural” process of progressing and aging, or from an “unnatural”

chronic or terminal illness. Whether death is perceived as natural or unnatural, it is an experience that unifies and impacts everyone. And whether we are educated in the ways of modern medicine or not, it is likely that attempts to rationalize our mortality and calculate our remaining time will conjure up the sensation of disconnect that Kalanithi describes so poignantly: “nothing about it seemed recognizable” (121).

This project hopes to illuminate the issues preventing a more open end-of-life discourse and, in doing so, reinvigorate conversations about death and dying and individual agency in the face of mortality. These chapters blend rhetorical criticism and rhetorical theory with popular contemporary sources in order to make an end-of-life discourse more recognizable, and ultimately, a more persuasive endeavor for modern audiences. As Cheryl Geisler writes, “Most scholars acknowledge...explicitly or implicitly, that recent concern with the question of rhetorical agency arises from the post-modern critique of the autonomous agent” (10). In a post-modern world, traditional views on personal agency are called into question. Geisler suggests that “Specifically, a rhetorical agent seen to make choices among the available means of persuasion is an agent rhetoricians can educate to make the best choices. The post-modern agent is not so obviously educable and, if not educable, what agency do we as rhetoricians have?” (15). The question of rhetorical agency is critical to the discussion of end-of-life because it is a question of “who has agency—and therefore responsibility”; as such, in order to pin down a post-modern sense of individual agency, it is “through work in a variety of non-traditional contexts [that] promises to enrich our foundational understanding of rhetoric” (11-12). In our post-modern society, rhetoric’s ability to educate necessitates that it cross boundaries and draw from untraditional sources. Although it is rooted in ancient



traditions, rhetoric must adapt. In order to develop a discourse that will be persuasive, scholars must draw inspiration from the not so obviously educable. The artifacts analyzed within this project were selected based on two criteria: authorial willingness to address end-of-life issues that met some public success and attention to individual agency as a critical facet of contemporary end-of-life discussions. Together, these considerations help construct a starting point for rhetorical intervention. Before delving into the case studies, it is essential to understand the cultural misconceptions that limit society's full participation in conversations about death and dying, and thereby increase the ethical imperative of this project.

### **Misconceptions**

If they consider it at all, most Americans consider death in the abstract, only gaining a more concrete understanding about what death is when it encroaches upon their otherwise death-free existence. As bioethicist George J. Annas writes, "We are a death-denying culture that cannot accept death as anything but defeat. This means we will prepare for any disease and screen for every possible 'risk factor,' but are utterly unable to prepare for death" (12). Due to the dramatic technological advances of the twentieth century, today, "terminal [illness] can be detected earlier and earlier in a patient's life, rendering the disconcerting reality of a terminal illness with few or no symptoms" (Dyehouse 208). Increasingly, death is present despite our rejection of it; recognition of this brings about a kind of paranoia over the definition and knowability of health. Jeremiah Dyehouse's discussion of illness in "Writing, Illness, and Affirmation" suggests that the experience of illness in American society—and other "societies with increasingly effective medical care"—makes interactions with modern medicine "equally strange for [the] doctors and

nurses” (209). In trying to familiarize and demystify this strangeness, locating the unknown is imperative.

There is a cultural perception that nursing homes, hospice, and other institutionalized forms of palliative care are widely available, easily accessible, and that they will be there when patients are in need of them. They are socially presented as viable, efficient options for end-of-life care. There is also a sense that they will provide individuals with a *dignified* death (dignity being an extremely loaded term that is highly individualistic and will be explored in depth within this project’s case study chapters). However, the availability of hospice and alternative care is not as widespread, and not the solution, that most Americans believe it to be. By and large, the locations where people actually die are hospitals, which many believe “dehumanize patients by silencing their voices and stripping them of their biographies” (Kaufman 95). In reality, each of these institutions has a tendency to shake up the individual’s sense of self and prevent their full participation in their care plans. Understanding how they function—and how they limit agency—is key in understanding end-of-life discourse.

The National Hospice and Palliative Care Organization (NHPCO), monitors hospices and certifies them only if they comply with federal regulations and meet basic standards of care. The NHPCO claims that “considered to be the model for quality, compassionate care at the end of life, hospice care involves a team-oriented approach of expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient’s wishes” (“About”). This expressly tailored care can be provided within the patient’s home (an option selected by approximately two-thirds of hospice patients), or in an institutionalized “home-like” setting in a hospice program’s facility.

Hospice care is covered by insurance, but is only made available to “patients who meet certain criteria”—namely, individuals who are terminally ill with a life expectancy of less than 6 months (“About”). According to the Preamble for NHPCO’s “Hospice Standards of Practice for Hospice Programs,” hospice “affirms the concept of palliative care as an intensive program that enhances comfort and promotes quality of life...when cure is no longer possible” (“Preamble”). Additionally, “hospice believes that death is an integral part of the life cycle and that intensive palliative care focuses on pain relief, comfort and enhanced quality of life as appropriate goals for the terminally ill” (“Preamble”). But this seemingly idyllic site of acceptance and compassion is heavily regulated and less easily accessible than it may seem. While Medicare’s federal website makes it clear that in order to enter hospice an individual must be given a prognosis of terminal illness with 6 months or less to live, what is made less clear is what is implied by entering into a required contractual agreement with hospice: “By signing up for hospice, patients generally agree to stop all disease-fighting treatments, such as chemotherapy or radiation” (Mayer 1). For individuals dependent upon Medicare, “you can get hospice care for two 90-day benefit periods, followed by an unlimited number of 60-day benefit periods,” but “at the start of each period, the hospice medical director or other hospice doctor must recertify that you are terminally ill (with a life expectancy of 6 months or less)” in order for the individual to continue receiving care from hospice doctors in home or at a hospice facility (“How Hospice Works”). If an individual’s illness goes into remission, then they no longer qualify for hospice and must leave. However, they can re-enter hospice at any time “if they are eligible”—meaning, if their illness has once again become terminal. Hospice offer the opportunity for an individual to remain in their own

home with occasional visits from healthcare professionals specializing in hospice's brand of pain management and palliation, but in order to receive this care, the individual must cease treatments which stave off illness. Hospice's primary concern is in eliminating pain—not in curing illness or fighting disease. Increased health and effective treatment eliminate the individual from being qualified for hospice care.

Nursing homes are also thought of as a viable option and location for the final phases of life. But nursing homes were established to do exactly what they advertise: nursing, not curing. As institutions, they prioritize matters like “avoiding bedsores and maintaining residents’ weight—important medical goals, to be sure, but they are means, not ends” (Gawande 75). Despite the fact that patients live within them, nursing homes are run more like hospitals than hospitable home-away-from-homes, and control over patients’ actions is key to their functioning as an institution. Not all nursing homes are created equal, though. As Atul Gawande explores in *Being Mortal*, “In the horrible ones, the battle for control escalates until [patients] get tied down or locked into your Geri-chair or chemically subdued with psychotropic medications” (76). In all too common nursing home horror stories, patients who annoy nursing home workers are stripped of dignity because of their individual needs. Gawande discusses how an elderly patient who needed assistance with frequent trips to the restroom was put on a schedule for urination and, when that did not succeed, put in diapers (78). “In the nice ones, a staff member cracks a joke, wags an affectionate finger, and takes away your brownie stash. *In almost none does anyone sit down with you and try to figure out what living a life really means to you under the circumstances, let alone help you make a home where that life becomes possible*” (76, emphasis my own). This making one's self at home is critical to the

experience of an individual's agency. To quote Jacques Derrida in *Of Hospitality*, "This is where the question of hospitality begins" (15). But unspooling the tremendous impact that the laws of hospitality have on end-of-life care can only begin once the structures inhibiting that hospitality (both socially constructed and literal ones), are more fully examined and understood.

Diane Davis offers another perspective on hospitality in *Inessential Solidarity: Rhetoric and Foreigner Relations*. For Davis, the question of openness to the other is one that necessitates "examining the implications of this always prior relation to the foreign(er) without which no meaning-making or determinate (symbolic) relation would be possible" (2). Rhetoric is not purely epistemological; Davis pushes instead for a different kind of rhetorical thinking, asking readers, "What would it mean for rhetorical practice, theory, and analysis if we were to acknowledge that communication in the most simplistic sense—as symbolic exchange—does not first of all lead to solidarity or 'community' but instead remains utterly dependent upon a sharing and a response-ability that precede it?" (2). Response-ability, for Davis, means that an individual is beholden to all others because of their openness. Hospitality is itself a kind of ethics. As Davis posits, for there to be any meaning sharing or meaning making between individuals, "a more originary rhetoricity must already be operating, a constitutive persuadability and responsivity that testifies, first of all, to a fundamental structure of exposure" (3). In this exposure, both the host and the guest are bound together by an ethics of behavior—but not conditions. As Derrida writes, "Between an unconditional law or an absolute desire for hospitality on the one hand and, on the other, a law, a politics, a conditional ethics, there is a distinction, a radical heterogeneity, but also indissociability. One calls forth,

involves, or prescribes the other” (*Of Hospitality* 47). But as Brooke Rollins carefully distinguishes, “There would be no conditional laws of hospitality, in other words...without an open and giving disposition toward the other *before* any instance of recognition or identification” (11). Conditions exist because the ethics of existing require openness—an exposed sort of living which leaves both parties too much at risk. Being too exposed, they must regain some control over interaction by implementing conditional interactions and leaving room for violence if it becomes necessary. Hospitality’s necessary conditionality undergirds the contemporary Western biomedical model, where encounters between exposed individuals become heightened by the very real risks involved. In entering the hospital, the patient is not warmly welcomed in a real way. Instead, by crossing the threshold, they become patients, and submit themselves to the rules of their hosts.

### **Disconnects in Existing End-of-Life Discourse**

Given glimpses into the available institutions of care in the United States, a vast gray area emerges. At their most basic level, modern hospitals are meant to keep you alive and hospice services are meant to help you to die. Still, “while most Americans would like to die at home, most die in institutions due to a chronic illness where death was the expected outcome” (“Preamble”). Institutionalized Western biomedicine has pathologized, or made abnormal, the process of dying to the extent that an individual’s death often reads as a failure. And this failure is not just one of the body, but is often discussed as a moral failing of sorts, too. One of the most well-known examples of this stigmatization of dying is Susan Sontag’s *Illness as Metaphor*. Sontag writes that, “Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the

kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place” (3). While we all rationally accept that illness might happen to us, and we might even take measures to prevent it from creeping in, it is not a reality that we spend a great deal of time discussing. Sontag suggests that rather than giving into the customary “punitive or sentimental fantasies concocted about” illness, a more appropriate response would be to recognize that “illness is *not* a metaphor, and that the most truthful way of regarding illness—and the healthiest way of being ill—is one most purified of, most resistant to, metaphoric thinking” (3). Instead, we should view death for what it is and, in our viewing, attempt to relieve ourselves of our guilt in dying. But this approach can require too much magical thinking—a sin that even Sontag was allegedly guilty of. Four years after her death, her son David Rieff wrote a piece in *The Guardian* called, “Why I had to lie to my dying mother.” In it, he shares a favorite phrase of Sontag’s: “‘There are some survivors, even in the worst cancers,’ she would often say during the nearly two years she received what for that time was an extremely harsh regime of chemotherapy for the breast cancer. ‘Why shouldn’t I be one of them?’” (1). Sontag had three different cancer diagnoses from 1972 until 2004. The first two occasions required drastic medical interventions, but Sontag survived. But rather than approach illness with the stoicism she prescribes for others, Sontag became a believer in her ability to overcome death. Rieff describes her as being “So terrified of death that she could not bear to speak of it” but also “obsessed with it” (2).

Sontag’s third diagnosis was myelodysplastic syndrome (MDS), a form of leukemia that is typically only treated by a successful bone marrow transplant. Sontag

believed that she could always be the “exception,” since she had twice come to see herself as the exception—and, therefore, to see her life as exceptional. Rieff writes, “my mother was about as far from Kubler-Ross’s famous and influential (not least among doctors themselves) five-stage theory of dying—denial, anger, bargaining, depression, and acceptance—as it was possible for a human being to be” (2). Sontag did not see dying as a process that she could go through, but as “extinction”—an option that was unspeakable and unfathomable. Despite her weighty consideration of death and the correct approach to illness in an intellectual realm, Sontag could not ready herself for her own death. Rieff writes:

But I was in her hospital room in Seattle when, months after the transplant, when she could not roll over in bed unassisted and was hooked up to 300 metres of tubes infusing the chemicals that were keeping her alive but could do nothing to improve her condition, her doctors came in to tell her that the transplant had failed and the leukaemia was now full-blown. She screamed out in surprise and terror. ‘But this means I’m dying,’ she kept saying, flailing her emaciated, abraded arms and pounding the mattress. So do not tell me she knew all along (2).

Sontag’s approach to illness as a reality for others contrasted with her impulse to rationalize away the possibility of her own impending death. “In her eyes, mortality seemed as unjust as murder,” her son writes (3). And, he also writes of the trauma induced by his mother’s inability to admit that she was dying—to herself, and to the loved ones she did not allow the chance to come-to-terms with her dying. While we might tell ourselves that dying is just another process in life, we cannot guarantee how we will approach our own death.

Those in need of the hospital’s curative medicine and those in need of hospice’s palliative care have more clearly defined medical needs than most. For those individuals whose health concerns fall anywhere on the spectrum between a quick hospital visit and a



quick hospice death, developing a care plan can be difficult. The needs of those patients are less clear and less easily defined. In *The Ethics of Need: Agency, Dignity, and Obligation*, Sarah Clark Miller describes fundamental needs, writing: “Not responding to fundamental needs results in serious harm to the individual” (47). And as Barbara Herman explains, “fundamental needs are ends that rational agents cannot forgo, namely, ends ‘that are necessary to sustain oneself as a rational being’ such as the continued ‘exercise of one’s agency as a rational being’” (qtd. in Clark Miller 47). These needs change the agent’s position from one who can operate for themselves to a one who is at least partially dependent: as Joan Tronto explains, to have a need is to require care (120). For individuals like Sontag, who might be able to conceptualize of dying as a *thing that happens*, but are not able to recognize it as a *thing that happens to them*, providing the right kind of care becomes imperative. And, “though care ethicists have provided many different definitions of care, Diemut Bubeck’s definitions of ‘caring for’ is perhaps the most accurate and complete” (Clark Miller 47). Bubeck’s caring for is “the meeting of the needs of one person by another person where face-to-face interaction between carer and cared for is a crucial element of the overall activity and where the need is of such a nature that it cannot possibly be met by the person in need herself” (Bubeck 129). Clark Miller builds upon Bubeck’s definition, stating that, “The process of caring involves two positions, namely, the position of the one who has a need (the ‘cared for’ or ‘care receiver’) and the position of the one who meets the need of the other (the ‘carer’, ‘caregiver,’ ‘caretaker’). The process is inherently interactive” (47). Importantly, “caring for oneself is not possible under Bubeck’s rubric,” since “care must necessarily be other-directed...care need not involve the affection present between friends and lovers, though

it might” (47). Instead, care is about inhabiting a perspective “of taking the other’s needs as the starting point for what must be done,” and then developing a plan of action with those needs in mind (Tronto qtd. in Clark Miller 47).

### **Alternatives and Outline of Chapters**

While Clark Miller’s depiction of an ethical style of caring-for is mainly geared towards her research with elderly patients, it is helpful in guiding a much needed conversation about all ill and dying individuals. An ethics-oriented approach to end of life can assist in providing a more just type of death because of the options it makes manifest. In reflecting upon his mother’s death, Rieff writes that Sontag’s inability to discuss death openly meant that “instead of dying in physical agony, my mother would have died in psychological terror, abject and inconsolable as she was in the first few days after her diagnosis” (3). This project reads this psychological terror as a complete rupture of the individual’s sense of self—a total loss of agency and control over one’s circumstances—and considers it one of the most unethical ways of dying in today’s society. Dying in psychological terror is arguably the most undignified way to die. It is a manner of death enabled by a lack of conversation about the alternatives.

This project hopes to bring existing alternatives into light by discussing end-of-life from a variety of perspectives. This project believes that the culturally pervasive rejection of death’s existence prevents individual agents from realizing the kind of death that they would consider dignified. In their diminished states of illness, they are incapable of making the same kinds of carefully weighed decisions that they would have made when illness-free. Growing nearer to death might help crystallize or reorganize one’s priorities, but rarely do these priorities include having full, frank discussions about the

kind of death one wants to experience and the kind of death that is attainable given the individual's circumstances. Issues of terminology arise when we consider who the agent of a death is; this specificity is intended to shift responsibility away from the physicians who are complying with the wishes of the patient or patient's family, or are following the care plan that they deem most ethically sound in that particular patient's case.

Ascertaining the agent of death is crucial, and is one of the most important aspects of determining cause of death. The homepage of the Death with Dignity Organization defines some alternatives to 'natural' deaths, or deaths that do not occur in hospitals or due to the removal of machinery. For individuals who wish to die another way, namely, the terminally ill, there are some heavily loaded terminologies to parse through.

Physician-assisted suicide (PAS), or assisted-suicide, is "an inaccurate, inappropriate, and biased phrase which opponents often use to scare people about Death with Dignity laws.

Because the person is in the process of dying and seeking the option to hasten an already and inevitable death, the request...isn't equated with suicide" (DeathwithDignity.org).

They stress that "the patient's primary objective is not to end an otherwise open-ended span of life" because something else is killing them. The American Public Health

Association concurs, stating that, "assisted suicide is inappropriate when discussing the choice of a mentally competent, terminally ill patient to seek medications that he or she could consume to bring about a peaceful and dignified death" (APHA.org). Suicide does

not work as a label, either, since it is intentional and voluntary but is a "permanent solution to a temporary problem" and as such, "ends a life that would otherwise

continue" (DeathwithDignity.org). Euthanasia "refers to the act of deliberately causing

the death of another person who may be suffering from an incurable disease or condition,

commonly performed with a lethal injection” (DeathwithDignity.org). ORS 127 states that, “Nothing in the [Oregon Death with Dignity Act] shall be construed to authorize a physician or any other person to end a patient’s life by lethal injection, mercy killing, or active euthanasia” (ORS 127). In order to fully understand the reasons why some Americans choose to take advantage of a little-known legal end-of-life alternative, the variations in how stakeholders define these alternatives are key. Death with Dignity does not neatly fit under the umbrella of PAS or assisted suicide, suicide, or euthanasia because by the time individuals come to seek out and take advantage of Death with Dignity, all other active options have been exhausted.

By analyzing existing fragments of end-of-life conversation from disparate sources, this project creates a working discourse about death and dying. This project is interested in the attainment of the ‘good death’ as an elusive concept which is pervasive in contemporary society but rooted in a cultural preoccupation with Socrates and Plato’s rendering of Socrates’ death. Today, understanding the ‘good death’ requires critical analysis of where individuals die, how death is determined, and how ‘natural’ death is obfuscated in favor of a more controlled end-of-life. In Chapter 1, Michel Foucault’s theories of bodily control within institutions add definition to the experience of the individual within Western biomedicine. Foucault’s work helps to illuminate the ways in which individual agency—for both healthcare professionals and patients—can become sublimated and even lost within the structure of the institution. Additionally, Foucault’s crystallization of the bio-power inherent within such institutions adds definition to existing controversy over end-of-life rights. Chapter 1 also ties these bio-power and the constraints of the institution to Jacques Derrida’s work on hospitality. The laws of

hospitality that govern typical human interactions are often disregarded within Western biomedicine, since taking the experience and wishes of the other into consideration would require individualized attention that the institution, as an institution, is not built to offer. Together, the confines of the institution, the pursuit of bio-power, and lack of care for the needs of the other create inhospitable system of care that prevents open discourse about end-of-life.

Chapter 2 seeks out the definition of the good death by analyzing one of the most venerated deaths in Western history: the *Phaedo*'s depiction of the death of Socrates. As one recent exploration of Socrates' death captures: "The charges, as far as we can reconstruct them, were vague: impiety, worshipping new gods, corrupting the young. It is startling that such accusations led to a death sentence: Athens was a radical democracy that prided itself on freedom of speech, and all that Socrates did was talk" ("Why Socrates Died: Dispelling the Myths" 1). Socrates' death has long been viewed—even celebrated—as a rational approach to an irrational situation. Upon being sentenced to death, he gladly accepted his fate and encouraged his followers to follow him to death as soon as possible. Despite the widely accepted reading of Socrates' death as an embrace of personal extinction, I offer an alternative reading of *Phaedo* as a document haunted by Socrates' anxiety over his own dying. This reading dismantles the contemporary end-of-life movement's embrace of death as a rational decision, and instead seeks to present a more honest conception of circumstances that could make a good death achievable.

Chapter 3 explores the contemporary end-of-life movement through Peter Richardson's 2011 documentary film *How to Die in Oregon*. Oregon became the first US state to legalize an end-of-life alternative. The law, which is known as the Death with

Dignity Act, allows healthcare professionals to prescribe terminally ill patients with medications that help them die. *How to Die in Oregon* follows numerous healthcare professionals and social workers who discuss the impact the law has on the care provided in the state of Oregon. Perhaps more importantly, the film captures the experiences of terminally ill patients who are seeking out the law to aid them in achieving the kind of death that they deem most dignified. Their narratives of illness dying are analyzed within this Chapter and complicate the place of hospitality in contemporary end-of-life situations. For those within *How to Die in Oregon* who work to provide this alternative, caring-for the other is rooted in providing access to whatever death that individual deems most dignified.

Chapter 4 focuses on the case of a 29-year-old Californian woman, Brittany Maynard. Maynard was diagnosed with an aggressive, incurable brain cancer at the age of 28. Although she initially attempted to seek treatment and surgery to eliminate the cancer, she received a prognosis of less than six months to live and a slew of grueling, debilitating treatment options. Rather than undergo treatments that she found unacceptable and inhospitable, Maynard and her family relocated to Oregon so that she could avail herself of the Death with Dignity Act. Simultaneously, Maynard became an outspoken advocate for increased end-of-life options. In the final months of her life, Maynard's image was splashed across popular publications and featured on numerous websites and news outlets. Chapter 4 discusses how Maynard's attempts to reinvigorate the end-of-life conversation have had a surprising impact since her death in 2014. Her rejection of inhospitable treatment from her home state of California, and the agency

afforded by her relocation during the final months of her life, add complexity to the end-of-life discussion—especially given the fact that most Americans wish to die at home.

In Chapters 3 and 4, illness provides individuals with a more purposeful kind of living due to their newly realized limits. This purposeful living is undercut by a profound sadness at all of the things that will be left undone. However, in Chapter 5, this notion is complicated by analysis of “Games,” an episode of the American television show *House, M.D.*, in which a renowned oncologist finds himself in the unique position of being able to tell a terminal patient that the original diagnosis was incorrect: the patient is completely cancer-free and is not going to die. The patient’s reaction to the doctor’s ‘good news’ is unexpected. Rather than embracing his new lease on life, however, the patient rejects it and is infuriated. Simply put, terminal illness had set him apart and made him special. Having a limited amount of life left had refocused his priorities and given him a freedom to fully live for the first time. Now, it is the limitlessness of life that is unacceptable and inhospitable.

As Vernon W. Cisney and Nicolae Morar wisely deduce, “the mechanisms of power always have a way of covering their tracks” (1). These chapters capture narratives that individually confront differing aspects of the contemporary end-of-life debate. When taken together, this project makes the importance of a new discourse of caring-for the end-of-life clear and lays bare the mechanisms of power which serve to encourage some discourses and eliminate others. By weaving together the written history, the documentary film, the autobiographical, and the fictionalized accounts, this project takes pieces of contemporary culture that society is already familiar and comfortable with and arranges those pieces in a way that produces meaning, rendering the subject matter

educable. This project does not advocate for any particular end-of-life method. Instead, it advocates for more transparent discussions concerning power and increased conversation about an individual's rights.



## Chapter Two

### **Bodies on Display: Agency and Hospitality in Western Biomedicine**

Michel Foucault's *The Birth of the Clinic: An Archaeology of Medical Perception*, begins: "This book is about space, about language, and about death; it is about the act of seeing, the gaze" (ix). Centuries after its inception, Western biomedicine remains deeply invested in space, language, and the act of seeing. One of the side effects of these investments has been an insulation of medicine, making the gaze—which Foucault defined as a specialized sight gained exclusively through medical training—a mechanism of control. In most instances, this kind of control over the body is beneficial for patients; however, when it comes to a patient's right to die, things become complicated. In "Controlling Death: Bio-Power and the Right-to-Die Controversy," Todd F. McDorman explores how those possessing the medical gaze attempt to use their specialized sight to determine not just an individual's particular health issues, but an individual's right to die. He writes, "At the forefront [of end-of-life] debates has been a power struggle between a social movement in favor of patient decision-making and institution entities reluctant to relinquish 'control' over the body" (257). Control over bodies is the purpose of modern healthcare. Whether healthcare professionals research and labor in order to keep bodies alive or to provide them with a dignified death, control is the motivating factor. Concern arises when the means of gaining control overwhelm the ends—and the individual being subjected to methods of care.

This chapter begins with an examination of Foucault's work on the history of institutions and the institutionalization of bio-power. Together, these two concepts serve as the foundation for the modern biomedical model. Society's dependency upon Western

biomedicine (the institution) and its agents (the bio-power) for care sublimates the needs of the individual in pursuit of doing the least harm for most of the people. As this chapter will explore, Western biomedicine's definitions of care can vary greatly. This is where Jacques Derrida's work on hospitality (and the scholarly endeavors inspired by that work) comes in: despite becoming increasingly dependent upon technology, individuals operating within the institution of modern medicine are still beholden to the countless others they come into contact with, and the countless others who their decisions will impact. This chapter brings the connections between the institution, bio-power, and hospitality into focus.

Medical facilities are spaces where patients seek help with medical issues, but they are also places where individuals with different levels of agency must interact and come to terms with their responsibility, or perhaps more accurately, response-ability, to one another. Whether intended or not, in caring for their patients, healthcare professionals make decisions with tremendous ethical consequences. The ethical dilemma arises when decisions are made *on behalf of* the patient, rather than *by* the patient or with the patients' wishes in mind. The distinction between making decisions and having decisions made by others calls the priorities of modern healthcare into question. As this chapter will discuss, research shows that an individual's sense of agency is at the greatest risk in times of crisis. Recent studies have illustrated the ethical concerns of medical professionals and how end-of-life in particular creates occasions for uncertainty. In, "Exclusive Ethics Survey Results: Doctors Struggle with Tougher-Than-Ever Dilemmas," evidence of doctors' ethical struggles within their professions was revealed. In the study, some 7,000 physicians were surveyed. Over half of the respondents felt that end-of-life issues placed

them in the most difficult ethical dilemmas and presented “the biggest quandaries,” with over a third of the respondents answering “it depends” to questions about providing life-sustaining therapy when it was futile, and ceasing or providing life-sustaining therapy due to familial demands (Kane 2). Additionally, 45.8% believed that physician-assisted suicide should be allowed “in some cases,” and 13.5% answered “it depends” to the same question. This means that almost two-thirds of the respondents felt that it was within the realm of possibility that their position as a practicing medical professional could include making decisions about ending a patient’s life or providing patients with access to particular life-ending materials (2). Dr. Thomas H. Murray, the President of The Hastings Center, a bioethical research institute, stated, “In medicine, doctors can do far more than they could in the past. They can do interventions that were unimaginable a few decades ago. Every time you give those kinds of power they come with difficult situations and tough ethical choices” (qtd. in Kane). Along with the rigorous training needed to become healthcare professionals comes the doctor’s involvement in some of their patients’ most stressful life experiences. The medical gaze equips healthcare professionals with a heightened sight. Foucault aligns trained discernment with medical knowledge, writing: “Medical rationality plunges into the marvelous density of perception...The eye becomes the depository and source of clarity; it has the power to bring truth to light that it receives only to the extent that it has brought it to light; as it opens, the eye first opens the truth” (xiii). In order to discern the causes of disease and illness, the viewer must be able to open up the obfuscating body and reveal the inner truth. The institution of medicine privileges this sight and in doing so, elevates the position of those who possess the medical gaze.

## **Agency Within the Institution**

The medical gaze gives healthcare professionals both the ability and the authority to make medical decisions. Despite the confidence that might make these decisions possible, the consequences of these decisions are not always readily transparent to healthcare professionals and patients. In fact, hospitals often have a significant disorienting effect on patients while simultaneously privileging the perspective and beliefs of hospital staff. Medical and legal scholar Hazel Biggs writes, “In any institutional setting individuals may be unusually insecure, and unfamiliar surroundings with unknown personnel and routines will almost inevitably impinge upon a person’s ability to act as an autonomous agent. In situations involving medical care, illness, lack of understanding, and fear may compound and intensify these insecurities” (99). While power over decision-making is something that most patients claim to want, during unexpected health crises or even the anticipated final stages of a chronic or terminal illness, individuals and their families often find themselves in vulnerable positions. The fear, anxiety, and lack of understanding studied by Biggs prohibit patients and their families from meaningfully advocating for themselves—a troubling side-effect of contemporary medicine that leaves the dependent parties unsure of how to verbalize their desires or negotiate their positioning, and therefore unable to participate in their own treatment. For most of these patients, discussions of death never occurred and interactions with Western biomedicine were limited.

Lacking a discourse with which to discuss their options or communicate their wishes, patients and loved ones can experience end-of-life as extremely disorienting and markedly inhospitable. In “Re-Examining the Agentic Shift: The Sense of Agency

Influences of the Effectiveness of (Self)Persuasion,” cognitive behavioral psychologists from the Netherlands and Germany present their research on the autonomy of individuals who had recently experienced a threat or injury to their sense of self. Through their research, they defined the somewhat abstract term ‘sense of agency’ as “the ability to recognize oneself as the controller of one’s own actions and to distinguish these from actions caused or controlled by other sources” (Damen 1). Their research revealed that an individual’s sense of agency becomes reinforced over time. It is through repeated behaviors and decisions made by that individual and, later, evaluated and reflected upon by that individual, that a sense of self is constructed. Therefore, an individual’s identity is formed, and reformed time and again, because of behaviors that they are able to perform. While a person might report maintaining a high sense of agency throughout long periods of their life, one’s sense of agency is not fixed; instead, “a sense of agency represents a state construct that binds together our thoughts, actions, and action-effects to give rise to the personal sense of having successfully influenced the immediate environment” (3). The study found that once a threat to an individual’s identity, or a decreased sense of agency, had been experienced, the individual was less sure of him or herself and measurably more susceptible to outside forces, especially when it came to suggestion and persuasion. Additionally, Len Doyal writes in “Medical Ethics and Moral Indeterminacy,” that there are weak and strong autonomies. Doyal’s research suggests that “all who have the ability to make ordinary everyday decisions in their lives possess weak autonomy, while strong autonomy attaches only to those who are able to scrutinize the information they receive in terms of impact and outcome, and thereby make fully informed choices” (Biggs 99). However, once an individual’s sense is ruptured, they will

be forced to recognize new limitations on their autonomy. So, these limitations on agency may be temporary, or they may become the new normal over a period of time. While medical professionals and patients both claim that patient involvement in decision-making is a priority for modern healthcare, what they fail to fully explain is when those decisions should be made. Ideally, decisions over one's health would be made when one has the capacity to fully understand and weigh their options—an approach that would allow for healthcare professionals and individuals to work towards common goals. However, due to the demands of the institution, this is not currently the case. Healthcare professionals do not uniformly recognize their ability—and responsibility—to equip all members of society with a thorough understanding of their medical options. Within Western biomedicine, healthcare professionals must meet the demands of two divergent camps that ultimately fail to acknowledge the human component of patient and doctor interactions. One views medicine as a business, and the other views it as a purely scientific pursuit. While both may be justified in their views, they also dramatically limit the kind of options available within the hospital setting. Within these two camps is an ever-present ethical concern over decision-making power.

### **Institutional Stakeholders**

At administrative levels within Western biomedicine, regulations exist to protect both patients and healthcare professionals and to provide the highest standard of care for all patients. On one hand, “stakeholders, including insurers, state and federal governments, and consumer advocacy groups, are expecting, and in many cases demanding, acceptable levels of performance in healthcare organizations,” (Goldsmith 27). On the other hand, these various groups “want to make sure that services are

provided in a safe, convenient, low-cost and high-quality environment” (28). Emphasis on cutting costs and avoiding patient “lingering” take a toll on the standard of care, though. An example of this is Roemer’s Law, a dictum that “famously and simply states, *hospital beds that are built tend to be used*” (Delamater et.al. 1). For patients and their advocates, Roemer’s Law could be used to increase the space hospitals devoted to patient care. Instead, the law bolsters the “belief that excess hospital beds leads to an *overutilization* of hospital services, when the observed demand outpaces the population’s actual need for services. Hospital utilization rates rise, therefore, due to higher levels of inpatient admissions which may or may not lead to longer stays, contributing to higher costs” (1). As an issue of space, this prevents hospitals from admitting and caring for patients who might be in need of professional medical interventions on the basis of lack of space. It also encourages hospitals to discharge patients who could benefit from more time spent within the hospital and under the care of hospital professionals in an effort to free up more beds more quickly.

Roemer’s Law adds complexity to one of the major conundrums within end-of-life care today: the location of death plays a significant role in the type of death that an individual experiences. Although they want to be cared for within hospitals, neither patients nor hospitals want the hospital to serve as the location of death. In 2000, a report was published in which Medicare claimed that the number of their chronically and terminally ill patients who were dying at home was on the rise. Since “public opinion surveys in the United States report that a majority of people would prefer to die at home if they were terminally ill,” Joan Teno and a team of medical ethicists conducted a decade-long (2000-2009) study on the site of death in order to understand what was

creating this new trend (Teno 470). In “Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Transitions in 2000, 2005, and 2009,” Teno and her team share a decade of careful research. Essentially, their research showed that while Medicare could justifiably report that more people were dying at home and approximately 65% of its dependents were dying in hospice care (doubling from 21.6% in 2000 to 42.2% in 2009), during the 10 years covered in the study, the number of times each patient was moved during their last 90 days of life tripled (Gleckman 128). Terminally ill and chronically ill patients were required to move, on average, three times during their last three months of life. This prevented hospitals from being the site of death on an individual’s death certificate, and allowed Medicare to make claims about improved end-of-life care without fully revealing their methods.

Additionally, the forced migration of terminally ill bodies prevented patients from “lingering,” a common practice in hospitals during the first half of the twentieth century. Lingered allowed patients who were very ill to remain in the hospital until they died—a process which could take weeks or even months (Kaufman 90). One particularly striking case: a nurse who began her lengthy career in healthcare spoke of a lingering patient she cared for in 1971, which was her first year as a nurse. The patient was a “young woman, dying of cancer, [who] stayed in the hospital several months to receive what would now be considered ‘comfort care’—turning, washing, toileting, and occasional pain medication injections” (91). The patient was not isolated from family during this time, but “had a husband and three young children, and no one expected her family to be able to care for her at home. She died in the hospital” (91). When lingering was a part of hospital protocol, nursing staff and doctors made attempts to help the lingering patients to



pass peacefully and humanely. However, Medicare's 1983 payment reforms left no room for "lingering", which was deemed "not a specific medical condition listed in the prospective payment system codes" and as such, "could not be reimbursed" (Kaufman 91). Today, regardless of the patient's individual circumstances, they cannot remain in the hospital unless they are receiving treatments (Kaufman). While it was common practice for decades, lingering would now be evaluated in terms of the availability of resources and the strain placed upon the institution if it were required to allow patients to linger. This reluctance to allow hospitals become the site for dying places the burden of care on other sources, such as hospices and nursing homes. As hospital protocols discharge patients who are too sick and unable to endure procedures—but are not yet succumbing to their illnesses—patients often find themselves without many viable locations for assistance. Within the contemporary hospital structure, there is no clear space in which the dying can experience the final phase of their lives. Much of the rhetoric surrounding end-of-life today represents dying as an inconvenience that Western biomedicine would rather not deal with, and it is reasonable to assume that patients recognize this lack of support while they hover in the in between, not encouraged to seek out hospitals for the relief of their pain or symptoms, but not always well enough to care for themselves. This lack of suitable location is one of the most overwhelming problems within contemporary healthcare. For those who are at the end-of-life due to old age or some terminal health issue, being forced to change locations so often is a clear sign that they are unwelcome. The lack of sensitivity shown to these individuals at their time of greatest need is a significant ethical dilemma, and one of the problems of the business-minded hospital model.

The other approach to Western biomedicine treats the endeavor of healthcare as a scientific pursuit. Barbara Heifferon and Stuart C. Brown write that, “As Western biomedicine developed into a scientific discipline, its humanistic origins and impulses have been downplayed. Empirical assumptions in the biological (including clinical) sciences have contributed to a dismissal of rhetorical attention” and increased focus on “scientific objectivity, student passivity, and dichotomous divisions such as subjectivity and objectivity” (Heifferon and Brown 3). Medicine has long been seen as a science. Foucault presents his history of medicine with a “deliberately both historical and critical approach...in determining the conditions of possibility of medical experience in modern times” (*BoC* xix). What *Birth of the Clinic* reveals about that the institutions established to provide healthcare is that their structure does not bode well for the needs of the individual body. Foucault discusses how medicine’s scientific focus, “gave to the clinical field a new structure in which *the individual...was not so much a sick person* as the endlessly reproducible pathological *fact to be found in all patients* suffering in a similar way...the plurality of observations was no longer simply a contradiction or confirmation, but a progressive, theoretically endless convergence” (*BOC* 37, emphasis my own). Despite the fact that modern medicine has debunked the idea of disease as ‘endlessly reproducible’, disease is often considered to present in universally similar ways across groups of people. Scientific medicine allows for these signs to be dissected by the expertise of the physician at the risk of the individual’s experience of illness.

### **Bio-Power**

What becomes obvious in parsing out the common interests of the more business-oriented approach to Western biomedicine and its more scientifically-oriented

counterpart is how invested both approaches are in reproducibility and doing the least harm for the most people. For both camps, medicine is successful if one approach works for all individuals—which is where Foucault’s concept of bio-power comes into focus.

Cisney and Morar suggest that, “The question of power, then, is traditionally one of domination, or the overextension of power’s reach. However, as Foucault rightly notes, domination occurs in myriad ways, at all levels of society” (2). So, “to truly get at the heart of power...requires not a general and totalizing interrogation of established systems of power, but rather a close and particular analyses of the fundamental, constitutive relations and mechanisms at work in localized settings, which make the establishments of domination possible” (3). Power, like an individual’s sense of self, is a fluid concept. It is not an external entity that pushes down upon individuals within a society, but a living thing that “flows through the lives of human beings, constituting the individuals themselves” (3). While “A number of sociologists and philosophers such as Marx, Nietzsche and Weber, have discussed the notion of power and have generally defined it in terms of repression and prohibition,” Foucault “defined it as a positive and productive force” (Perron et. al. 536). In particular, Foucault’s work on bio-power “encompasses many indicators of interconnectedness between individuals and the state” or institution (536). Bio-power is characterized by “the interconnection of two axes: *anatomo-political* (discipline of the body) and *bio-political* (population management)” which, when taken together, focus and organize power over life. Bio-power scales to fit any population, and in the case of the Western biomedical institution, it serves to both discipline the body and exercise control over matters of life and death.

Bio-power is not used to control through repression and prohibition. Instead, it is a tool for the improvement—and, really, the standardization—of the masses. In bio-power, “The human body comes to be seen as a machine, complete with functions and utilities, inputs and outputs, predictabilities and precisions”—a disciplined and disciplining location of power (Cisney and Maror 4); when taken together, these disciplined bodies form “a global mass that is affected by overall processes characteristic of birth, death, production, illness, and so on” (*HoS* 193). When bio-power emerged in history (around the middle of the eighteenth century, the same approximate time as the birth of the clinic), so too emerged “a host of disciplines and bodies of knowledge whose task is to calculate, interpret, and predict the overall *health* of society writ large” (Cisney and Maror 5). Power becomes centered “not on the *individual* living body but on the *species-body*” (5). Through discipline and regulation, “the modern incarnation of power relations, labeled as *biopower*” emerges (5).

However, the idealistic vision of bio-power as a regulatory mechanism of social good is undermined by the body’s susceptibility to failure. As Foucault discusses, “The sick man is no doubt incapable of working, but if he is placed in a hospital he becomes a double burden for society: the assistance that he is given relates only to himself, and his family is, in turn, left exposed to poverty and disease” (*BoC* 18). Additionally, he writes that “the hospital...creates further disease in the social space in which it is placed. This separation, intended to protect, communicates disease and multiplies it to infinity” (19). When they were started, hospitals were places where disease spread like wildfire in spite of efforts to exercise control; the bodies depending upon the institution and the institution writ large were vulnerable to disease and illness. But Foucault’s analysis also illustrates

that a man's value is often calculated based upon whether he is healthy and whether his healthy body can be put to work for the good of the state/institution. Rather than focusing on curing the individual, "the patient, with his peculiarities of age, sex, and personal history, represented an interference that had first to be abstracted before the pure nosological essence of the disease could be revealed" (Sheridan 28). The emphasis on bio-power gave way to "a new form of political and social organization...dependent on the pushing to the limits of all human capacities;" bio-power "seeks the consistent and ongoing increase in the forces of life without thereby suffering the loss of control over these forces—power in the service of vitality" (Cisney and Morar 6). Within contemporary society, bio-power permeates citizens at both the individual and the societal level; bio-power stems from and engages with "an explosion of numerous and diverse techniques for achieving the subjugations of bodies and the control of populations" (140). In order to thrive, individuals must become part of a group. Institutions dependent upon bio-power for their survival—including Western biomedicine—"normalize, structure, optimize, and subordinate the forces of individuals to enter them into the machine of the economic system, to make them *productive members of society* who will happily defend it to the death if necessary" (7). One's willingness to fight to the death to protect their rights to remain a productive part of a society is particularly interesting when we consider that for many of the individuals in society who find themselves struggling with terminal illness or end-of-life, the fight is not intended to hasten death, but to gain control over it. Often, this control is an individualized one that effectively removes the individual from its subjectivity as a productive member of society and reconstitutes them as a subject apart—a member of a

different type of group, even. In a society that privileges health writ large, individuals who become terminally ill become the *living dying*. Centuries ago, when individuals were not contributing and their needs risked the collapse of the familial bio-power, they were institutionalized, or set aside in order for the group to move forward (*BoC* 19). In contemporary culture, they are welcomed into hospitals—but only if they submit their bodies to the hospital’s regulations. Often, regulations include undergoing any and all procedures suggested by nursing staff and physicians. Patients may no longer be admitted to institutions against their wills, but they are now precariously dependent upon those institutions for access to remedies. For the *living dying*, discipline and regulation must be reconfigured.

Healthcare professionals are just as susceptible to the pitfalls of bio-power as their patients are; after all, they too are human. As recent research suggests, it is this humanistic impulse that forms some of the conflict in the practice of Western biomedicine. With increasing frequency, healthcare professionals are reporting serious ethical dilemmas during the performance of their jobs. Paul J. Weithman writes that, “The Harvard Classics edition of great papers in the history of science reprints a version of Hippocrates’ famous Oath” (548), and that included in the Oath are commitments to a certain set of behaviors and standard of care. Among them: “I will follow that system of regimen which, according to my ability and judgment, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous,” “I will give no deadly medicine to any one if asked, nor suggest any such counsel; and in like manner I will not give to a woman a pessary to produce abortion” (Hippocrates qtd. in Weithman 548). What is striking within this excerpt is how significantly life has changed since the

Oath was written. Still, the Hippocratic Oath remains one of the major ethical arrangements in present day. Doctors who violate any part of it (in its contemporary state) are deemed unsuitable to practice medicine; with a violence, they have rejected the laws governing the practice. These are not the only rules that doctors risk breaking. The tremendous responsibility associated with the practice of medicine holds doctors hostage to a standard of behavior, and of responsibility. One of the main problems within Western biomedicine is the distrust that stems from doctors manipulating their responsibility by not reporting when mistakes are made, or by making decisions without fully explaining consequences to patients. Most medical professionals adhere to what Katherine Foss has dubbed the “code of silence” (Foss 485). By not making medical errors a part of the public record, medical professionals maintain an air of perfection: recent Institute of Medicine (IOM) reports found that “flaws in the healthcare system, not incompetent individuals, have created a situation that breeds medical errors” (qtd. in Foss 485). These flaws are not widely reported, though; doing so would undermine the façade of control created by regulatory bio-power. Additionally, further research suggests that “the medical profession’s tradition of hierarchical medicine may discourage physicians from listening to patients’ concerns and may encourage medical residents and junior health professionals to attempt new procedures in order to ‘prove’ themselves as physicians” (Emanuel and Emanuel). These findings bring about important questions. For starters, if the professionals working within Western biomedicine are required to strive for unattainable perfection, how can the system be fixed to accommodate a more humane approach for all of the disciplined bodies within bio-power? Currently, medical errors—when admitted—are seen as deeply incongruous with the public’s image of medical

perfection. It follows that in being held to impossibly high standards whilst being protected by the auspices of Western biomedicine, healthcare professionals might be missing the reality of the patient experience. Because “Discipline, it is true, intervenes directly on the forces of the body itself to challenge and optimize them. At the same time, it does so precisely to the end of situating that particular body within a hierarchy that precedes it” (Cisney and Morar 9-10), the endeavor to discipline bodies that are not capable to be optimized makes matters worse. After all, “Disciplines constitute a system of control in the production of discourse, fixing its limits through the action of an identity taking the form of a permanent reactivation of the rules” (AoK 224). If individuals cannot be disciplined through curative medicine or other life-saving measures, their bio-power is diminished and their position in society precarious. As the next section of this chapter will discuss, the fixed limits best suited for discipline are made manifest in both literal and abstract ways, since, “A discipline, in other words, serves as an apparatus for producing discourse *by controlling the way in which the discourse is produced*” (McGushin 628, emphasis my own). By striving to control and discipline bodies, society has allowed the institution of Western biomedicine to exercise almost complete control over end-of-life, right down to the words used to discuss it.

### **Hospitality + Bio-Power**

Bio-power’s influence over contemporary life is apparent, and the structure of contemporary healthcare is an institution that functions because of its ability to discipline and regulate. These facets of healthcare are intended to help the masses, but in attempting to construct a system that benefits all subjects dependent upon it, the power wielded by Western biomedicine has taken a more prohibitive, repressive approach. In order to



liberate Western biomedicine, its practitioners, and its patients from the institution's overextended power, it becomes necessary to liberate the individual. Doing so means turning towards theories of the self and hospitality, and utilizing research on sense of self, agency, and institutions to help untangle some of the knottier aspects of contemporary Western biomedicine. In the remainder of this chapter, exploring what is made possible by the openness of the subject is integral in moving towards this project's main goals: reclaiming control over bodies that subvert standard discipline, thereby establishing a discourse with which to discuss end-of-life.

In *Inessential Solidary: Rhetoric and Foreigner Relations*, Diane Davis writes: "For there to be any sharing of symbolic meaning, any construction of a common enemy or collective goal, any effective use of persuasive discourse at all, a more originary rhetoricity must already be operating," and this opening must be "a constitutive persuadability and responsivity that testifies, first of all, to a fundamental structure of exposure" (3). In being, being-with, and being-towards the Other, individuals open themselves up in ways that expose, that lay bare individuality, and create vulnerability. In being rhetorically open, subjects open themselves up not just to the Other, but also to the customs and regulations which discipline life and construct society. Ethics should serve as the guiding principle for the construct of the self; since, as Foucault writes, "constituting an ethics of the self...is an urgent, fundamental and politically indispensable task" (*CdF*82 241). McGushin builds upon this claim, stating that, "Given our current political and ethical situation, an ethics of the self would represent one critical point of resistance" to existing power structures (630). He continues: "What's more, a proper understanding of power and the points of resistance to power must work with a

notion of a 'subject who would be defined by the relation of the self to itself.' In other words, according to Foucault, we need a concept that functions both at a discursive or theoretical level, allowing us to comprehend the function of power, and that functions at a 'real,' practical level as a tactical intervention in the deployment of resistance to power" (McGushin 631, Foucault 241). For individuals who enter an institution in need and with some goal in mind, hospitality serves as both a theoretical principle and a practical point of resistance.

As discussed earlier, an individual subject's sense of self is fluid and, due to the individual's exposedness, vulnerable. When we enter a medical facility for assistance in a medical issue, for example, we are aware that we are entering an institution with structured rules. In order to receive the treatments we desire, we must abide by these 'house rules.' In this sense, the space of medical decision-making has much in common with hospitality. In 2000, Jacques Derrida stated in the *Angelaki* essay "Hostipitality," that "hospitality is opposed to what is nothing other than opposition itself, namely, hostility...The welcomed guest is a stranger treated as a friend or ally, as opposed to the stranger treated as an enemy (friend/enemy, hospitality/hostility)" (4). The relationship between enemy/friend, hospitality/hostility, represents a blurring of the fluid boundary between the two, or what Derrida called "hostipitality." Derrida states that, "hospitality is certainly, necessarily, a right, a duty, and obligation, the *greeting* of the foreign other as a friend ...on the condition that he maintains his own authority in his own home" (4). Additionally, within the hospitality/hostility binary, the host "thereby affirms the law of hospitality as the law of the household, the law of his household, the law of a place (house, hotel, hospital, hospice, family, city, nation, language, etc.)...namely, the *being-*

*oneself in one's own home*, the condition of the gift of hospitality” (4). In a sense, patients enter the hospital and become guests, which is why in Western biomedicine today, “doctor and patient are caught up in an ever-greater proximity, bound together, the doctor by the ever-more attentive, more insistent, more penetrating gaze, the patient by the all silent, irreplaceable qualities that, in him, betray—that is, reveal and conceal—the clearly ordered forms of disease” (*BoC* 16). Upon entering the domain of the hospital, doctor and patient are inextricably linked in a hospitable relationship; but, since the patients are heavily dependent upon the specialized sight that only the trained medical professional can provide, the power within the relationship is asymmetrical. This imbalance in power has been around for centuries, and is one of the primary ethical dilemmas within contemporary medicine.

Hospitality requires us to admit the existence of the ‘foreign other,’ or the entity who is simultaneously different and separate from us, and whose existence makes it possible for us to understand our own *being-oneself*. Derrida makes clear that, “hospitality is a self-contradictory concept and experience which can only self-destruct <put otherwise, produce itself as impossible, only be possible on the condition of its impossibility> or protect itself from itself, auto-immunize itself in some way, which is to say, deconstruct itself—precisely—in being put into practice” (5). Much like *being-towards-death*, hospitality functions because it operates under the theoretical assumption of its infinite possibility, but it is made real in its recognition of its finitude. The spaces that Derrida claims as spaces of hospitality become both figurative and literal, as Derrida makes clear in an aside during “Hostipitality,” when he asks his audience to consider “the figure of the door,” and clarifies that, “for there to be hospitality, there must be a door.

But if there is a door, there is no longer hospitality. There is no hospitable house. There is no house without doors and windows. But as soon as there are doors and windows, it means that someone has the key to them and consequently controls the conditions of hospitality” (14). In the realm of the real, hospitality is not a figurative door, but a literal one. As Brooke Rollins describes, states and institutions have long offered foreigners “a system, a status, and even certain protections and honors that constitute what Derrida calls ‘hospitality by right’” (Rollins 7). Hospitality by right “pulls welcomed guests into an economy of reciprocity—even violence. When the state extends rights to foreigners, that is, it does so by virtue of its sovereignty and by requiring the foreigner to recognize and submit to that sovereignty” (7-8). These conditional rights, then, require that visitors submit to the rules of the space they wish to inhabit and find protection within. And within particular spaces, one’s role is altered—one’s identity is shifted from that of subject with independent agency to that of a subject/guest who is beholden to another, sovereign subject/host. These shifts make it necessary to know the customs of hospitality, and to prepare one’s self for the violence of hostility in the event that a misstep is made or that transgressions of violence occur.

When patients and loved ones enter hospitals for treatment, the repetition that stabilizes their identities is interrupted. They are now subject/guests who are dependent upon healthcare professionals/hosts and the sovereign hospital—not agents free to act as they wish to in the world outside of the institution. By entering the space of the hospital, individuals are stripped of certain rights, but privy to new protections. This is the trade struck in pursuit of staying alive, and it marks the beginning of the difficult-to-escape cyclical relationship that is contemporary Western biomedicine. Additionally, since the

sense of self is particularly vulnerable in situations and spaces that are new and disorienting, an intervention on behalf of patients and for the protection of their rights becomes necessary. If not handled with care, patients' sense of self within the setting of the hospital can become deeply injured during a hospital stay. While patients know that they need what the hospital is offering, they do not know what the means to the end will be. And, patients and their loved ones do not always possess the skill set, wherewithal, or time to make the most informed decision in their particular circumstance. In terms of conditional hospitality, contemporary hospitals place myriad restrictions upon a patient's agency while asking/requiring that the patient willingly submit to whatever treatments and procedures the doctor decides upon.

The social constructs disciplining each individual's behavior also play a role in the conditioning of their bodies. In medical interactions, bodies enter into an occasion of hospitality where the stakes are often, and quite literally, life and death. If, as Davis explores, a collective or community "consists not in shared essence or common being (or even a common purpose or interest or practice or value) but in a sharing out (*partage*) of being itself," then Western biomedicine as a construct can only exist through the sharing of those individuals depending upon it (Davis 5). It is this sharing outward that marks the beginnings of hospitality; the outcome of this hospitable interaction is the metric that can and should be evaluated for its aptitude in caring-for all the others in its facilities. Issues of health and illness are among the most identity-shaking and agency-rupturing experiences endured by members of modern society. Medicine has both a comfortable and a foreign power over human bodies. Foucault posits an interesting approach to medical authority within *Birth of the Clinic*. He asks, "Is a medical experience, diluted in

the free space of society reduced to the single, nodal, and necessary figure of the family, not bound up in the very structure of society?” (19). He goes on to discuss the ideal medical model: one where “a certain supervision would be exercised over the doctors themselves, abuses would be prevented and quacks forbidden to practice, and, by means of an organized, healthy, rational medicine, home care would prevent the patient’s becoming a victim of medicine” (20). But no structure, once placed in the hands of man, operates ideally. In medicine, the medical gaze provides doctors with a specialized vision, a kind of superpower which allows them to discern things about and within the body which the individual cannot know about himself. Instead of educating citizens about their bodies and bodily conditions, Foucault writes that the gaze shifted from the old practices of guessing, interviewing the patient, or a reading of outward symptoms, to something more institutionalized:

“[T]he medical gaze...was no longer the gaze of any observer, but of a doctor supported and justified by an institution, that of a doctor endowed with the power of decision and intervention. Moreover, it was a gaze that was not bound by the narrow grid of structure...it was a gaze that was not content to observe what was self-evident; it must make it possible to outline chances and risks; it was calculating.” (89)

The calculating nature of the medical gaze provides doctors with the training *and* institutional backing to make claims as to what the patient’s maladies are and how they can best be solved. The authority to visualize illness lies with the medical professionals who can diagnose, order tests, and interpret results—as does the right and responsibility to select what kinds of tests and procedures will be offered to patients. This ability to discern and interpret is of great importance in certain medical situations, and when used responsibly for the greater good, the medical gaze is an invaluable tool. Through the medical gaze, surgical processes can safely (and accurately) occur and patients’ lives can

be saved. Microscopic evidence of illness can be analyzed, and symptoms can be validated through the scientific training of the professional healthcare staff. However, because the medical gaze depends heavily on the individual doctor's abilities as a careful calculator, reliance of the masses upon the calculations of the few create a strange dynamic which still governs—for better or worse—much of our contemporary medical model.

### **Hospitality + Healthcare**

Research on patient and doctor relationships suggests that autonomy and personal agency are critical in providing patients with dignified care, and dignified end-of-life care in particular. As explored earlier in this chapter, within American culture, dignity is very closely tied to the ability to make decisions on one's own, or to maintain a high sense of agency. In "The Common Harm in Bioethics and Public Health," authors Wasson and Cook write, "Western society allows people to undertake risk or harm to themselves to some degree without intervention," but that public policies are put in place "to limit the common harm rather than promote the common good" (Wasson and Cook). It follows that if patients cannot fully analyze the information they are being given at what is potentially a very emotional, difficult time, their choices may not be fully informed. And, since the common good is the motivating factor behind medical decisions, individual needs receive less and less attention.

As previously discussed, location of death is important. Timing is as well. But in a culture that is thoroughly death averse, conversations about end-of-life care between patients and their doctors—or patients and their families—do not always take place in a timely manner. If they do occur, they are not always fruitful. Patients do not always ask

questions, and “even when patients do ask for information, they ask general rather than specific questions, which are likely to yield general rather than specific answers” (Feeser 3). Living wills or advanced directives are in place for some patients, but in terms of *specific* care options given *specific* medical circumstances, most “patients and families, when faced with health crises and the surrounding plethora of medical options, *do not know what to want*, other than recovery” (Kaufman 34). In addition, there is “confusion over what actually constitutes comfort care or palliation, and whether that set of practices can be separated from unnecessary, optional, or unwanted life-prolonging interventions, creates dilemmas for physicians” (38). A recent study suggests that, “The advantages of hospice care are diminished for terminally ill patients who enter either prematurely or too late. In general, premature hospice referral represents a lost opportunity for the patient to receive potentially effective and life-prolonging treatment. Conversely, late hospice referral is not desirable and negatively impacts both the quality of end-of-life care and the quality of life of patients and their families” (Gil-Herrera et.al. 2). However, individuals are not always fully aware of the optimal window in which they should take advantage of hospice care; this is further complicated by terminally ill patients’ dependence upon their insurance coverage. Even if their insurance covers end-of-life care, “according to Medicare regulations, patient eligibility for hospice care is contingent upon a life expectancy of less than six months, as estimated by the attending physician and certified by the medical director of the hospice program” (2). One of the main motivations for entering hospice is that option’s alignment with one’s personal values, which “determine the choices they make from a range of” readily available “end-of-life treatments” (Norton and Miller 252). But hospice is not easy to be admitted to, and in the event that the



patient does not die within their 6 month window, things can become complicated. For instance, hospice caregivers deal with patient death up close, and in one study, revealed that they suspected patients of taking advantage of unapproved methods to end their lives (252), such as when a “bottle of morphine and a fifth of gin” are easier to attain than materials needed to medically end life in a quicker way. Others discussed hospice’s difficulty in providing patients with the end-of-life they desired, stating that sometimes, even those patients who were of sound mind, “deliberate,” and “had already negotiated with themselves about what their terms of living and dying might be” were unable to achieve their desired death because of practical limitations (253). For the terminally ill and the dying, hospice seems like a humane and comforting way to die. However, it is still an institution of medicine and has its own standards to uphold. And these standards include avoiding behaviors which might speed up dying process. For individuals who assume hospice will be available for them at the end of life, there seems to be a lack of understanding about what hospice is and what it can provide.

And lack of transparency about healthcare coverage and possibilities for admission into hospice are only made more difficult because of the diagnostic and prognostic methods used by practicing healthcare professionals. In “Rough set theory based prognostic classification models for hospice referrals,” Gil-Herrera et. al. performed reviews of prognostic methods and discovered that, “despite the importance of accurate prognostication within the spectrum of medical care objectives, there is a lack of accessible and accurate prognostic models available to physicians in practice” (3). This is particularly problematic because of patient dependence upon those methodologies at the end-of-life. It is crucial that patients be given a clear understanding of what will occur

during end-of-life, and realistic expectations about what medical interventions can accomplish. However, while “ethical, legal, and societal concerns greatly affect the framework under which medical data may be used,” the “US model encourages the use of de-identified, minimal risk medical data for research purposes, specifically data collected during routine treatment of patients” (3). Additionally, there is a lack of clarity in the translation and transmission of information, since “patient-specific disease progression over time is not considered,” leaving room for too much ambiguity in patient’s approaches to their own experience with their singular disease.

At the end of their study, Gil-Herrera et.al. offers a cost-benefit analysis to their mathematical model of prognostics. It serves as an uncharacteristic aside within the journal *BMC Medical Informatics & Decision Making*, under the heading “Decision analysis for hospice referral.” They write: “Consider the costs—economic, emotional, and physical—associated with the decision to enter hospice care. These costs are justified for patients who either enter hospice care at the *appropriate time* or for those who do not enter hospice care when they could benefit from curative treatment” (18, emphasis my own). The article defines these instances as “true positive and true negative” outcomes, but then moves on to a discussion of the more likely occasions—those in which “a higher emotional and physical cost is born by patients sent to hospice care but who ultimately survive six months—a false positive” (18). Still worse, though, comes the “highest cost of all, emotionally, economically and physically,” which is “born by the patient and his or her family when costly treatment is prolonged for a patient who should have been referred to a hospice care program—a false negative. In this last case, some or all of the benefits of hospice care would be lost while the stresses and economic burden of

aggressive treatment are endured” (18). For these false negative patients, remaining time left to live can become squandered on treatments that only hasten death and increase suffering.

As the patient safety officer at Maine Medical Center recently stated, “Forty years ago, hospitals were looked at as trusted friends. But there has been a relative decline in positive feeling about hospitals, because of all the attention to medical errors, the fear of hospital-acquired infections and the commercialization of medicine” (Salvador qtd. in Pear). While hospice is a viable option for many individuals, its usefulness is limited. And the fear associated with hospital deaths is not completely unwarranted, given the lack of individualized care. In order for hospices or hospitals to provide a dignified death for every single individual, patients would need to die in a perfectly orchestrated way—the kind of death reflected in the prognostic materials which do not take individual experience or needs into consideration, but instead de-identify unique, personal diagnoses and prognoses. Basically, individuals would need to enter the hospitals with dying as their purpose—not curative medicine. While hospice is often a place ill individuals go with dying in mind, and although it aims to be hospitable, as an institutionalized method of care, it only welcomes in a very particular kind of guest. And, in welcoming them, the institution cannot guarantee the guest’s experience. As host, it cannot protect the guest from death, but instead promises only to make death a little less painful, a little less lonely, a little closer to a dignified ending. Hospice hospitality only succeeds if it is a true positive—which is not as easily orchestrated as most Americans would like to believe. Ironically, even when hospice patients have found in-home hospice solutions to ease their end-of-life experience, there are many risks due to the lack of oversight occurring within

the home setting. As Gershon et. al. report in “Home Health Care Patients and Safety Hazards in the Home: Preliminary Findings,” despite home health care being the “fastest growing sector in the health care industry,” it also poses some serious issues due to “home care delivered under conditions that may be uncontrolled...health care providers [with] limited training or expertise in the area of patient safety and [who] often have little or no direct supervision,” and because while each individual’s home might technically be a “worksite, all the necessary health care workplace protections for both workers and patients may not be in place or readily available” (2). Home health care and home hospice offer a liberation from the institution, but it is also that liberation which makes the quality of care offered by in-home services problematically ambiguous. This only further complicates the relationship between patients and caregivers, leaving a vast ethical end-of-life gray area in which experts, patients, and loved ones are currently stuck.

Dying is not always a medical emergency. In many cases, death occurs in a way that is “natural,” or that can be interpreted as an ending to short- or long-term suffering, or in some fortunate cases, an ending that is free from suffering altogether. But when death does not occur naturally, a situation which modern medicine has caused to become increasingly common, patients need to understand what conditions they will be responsible for adhering to upon entering the hospital. And, they need to be able to speak the language of the hospital in order to explain themselves. In the 1984 study “Paternalism and Partial Autonomy,” O’Neill writes: “One patient can indeed be expected to come to an informed and autonomous (if idiosyncratic) decision; another may be too confused to take in what his options are. A third may be able to understand the

issues but be too dependent or too distraught to make decisions” (O’Neill 177). Biggs builds on O’Neill’s research, writing that, “when stripped of clothing, familiarity of surroundings and emotional support, patients can find it difficult to express doubts and fears about the efficacy of proposed forms of treatment” (Biggs 99). Hospitals are disorienting places and when individuals enter hospitals, they are often not completely in control of their emotional or physical wellbeing.

Douglas Davies writes in *A Brief History of Death*, “most ordinary folk do not have the luxury of being able to [express themselves] in response to death. Whatever their private thoughts may be, the public world stands as the arena in which those relationships have to be expressed, catching as best it may the nuances of personal experience” (Davies 4). Sociologists and psychologists have long described mortality as an important human experience that we can only fully understand as we mature and recognize the mortality of those around us and, inevitably, our own. But, as psychologist Nima Golijani-Moghaddam reports in “Practitioner psychologists in palliative care: Past, present, and future directions,” Westerner’s “familiarity with death has decreased over recent generations” and “increased life expectancies and the relocation of death from family homes to care institutions mean that direct experience of death is typically avoided until mid-life” (Golijani-Moghaddam 32). Death is dramatically less visible in Western culture today than it was in Western culture just 50 years ago. Sociologist Tony Walter suggests that this is due to the change in the location of death: instead of dying at home, Westerners now view death as a stage of life that occurs in a hospital or institution. Walter characterizes this shift in location as a shift in culture—from the ‘traditional’ model of the family caring for their dying loved ones to the ‘modern’ model where the

dying are cared for by doctors, heavily medicated, and where suffering and death is hidden from the public view (Walter). This cultural shift has removed death from the public sphere, but has one more striking consequence: it has prevented individuals from developing a full understanding of their mortality and how it might naturally progress. Due to this shift to the ‘modern’, contemporary people are ill-equipped in dealing with death because it is culturally invisible. Before this shift, death was something that individuals learned about as they aged and people around them also aged and died; first, much older people who were distant relatives and gradually, individuals who were closer in age and station to the individual himself succumbed to the natural order of things (Goljani-Moghaddam 34-35). Once dying was confined to institutions and made less visible, the culture shifted from concern over saving people from diseases that might kill them within a few days to what Tony Walter describes as a cultural struggle to learn “to die more slowly from the degenerative diseases of old age” (Walter). While healthy individuals might take advantage of contemporary medicine’s ability to provide them with solutions to manageable health issues, for the terminally ill, dying more slowly is not always an option.

In pursuit of a more hospitable model of death in America today, we must find a language that assists in creating transparency. However, developing a discourse about death and end-of-life presents its own challenges. In 2009, Americans had begun to warm to the idea of educating themselves about death when the House of Representatives attempted to pass new healthcare legislation, HR Bill 3200. A provision, 1233, was one small piece of the HR Bill 3200. 1233 effectively spelled out how to train physicians in end-of-life patient conversations, but also presented options for incentivizing these vital

conversations (HR Bill 2300). Additionally, it encouraged doctors to voluntarily provide their patients with information about end-of-life, living wills, advanced directives, and other medical and legal options. But the bill unraveled when then-Republican Vice Presidential candidate Sarah Palin referred to the provision as creating “death panels,” which would allow physicians to decide which patients were “worthy of medical care” (Palin qtd. in Millman). Although Palin’s claim was refuted by all medical, political, and legal sources involved with the bill and provision, the public uproar caused the provision to be removed in order for the rest of the bill to be passed. It wasn’t until five years later in 2014 that the Institute of Medicine called for an “overhaul” of how end-of-life care is dealt with in the United States. Additionally, a December 2014 *Newsweek* article claimed that 2014 was, “The year we finally learned to talk seriously about death” (Millman). Despite this hopeful declaration, there have been no substantial alterations in how death is coded or in how it is discussed.

Contemporary medicine is now confronted with the largest group of Americans over the age of 65 in history. In the face of this new societal structure, one of the questions medicine should be asking is this: How can dying be made more hospitable and approachable? A 2011 report in *Clinical Teacher* found that various medical school curricula recognized a growing “lack of opportunity for students to explore death as members of society rather than future practitioners” (242), and Trinity College in Dublin in particular found it necessary to introduce a completely new set of courses on Death and Dignity in order to assist students in providing better end-of-life care. The report describes their need, saying, “[r]ather than discussing well-worn roads of ethics of euthanasia and palliative care, this course afforded students an opportunity to perceive

death as a *normal societal event*, rather than an event that required intervention by the medical profession either by preventing, prolonging, or easing death” (242, emphasis my own). If current and future doctors struggle to recognize the normality of death, then it follows that their methods of care might be influenced by this lack. A recent study in the “communicative competence” of healthcare professionals in the delivery of “bad news,” found that “Bad news is typically defined as information that ‘negatively alters’ the patient’s perspective of his or her future” (Gillotti et. al. 1013). In comparison to other doctor-patient interactions, the “interaction still involves information giving and seeking, as do most medical consultations, but the emotional component and subsequent patient retention are different than other medication interactions” (1013). In attempting to develop a better methodology for the delivery of bad news from doctors to patients, Gillotti and her co-authors admit, “not much is known about the actual training of health care professionals in this area” (1013). It should come as no surprise, then, that research has shown “one of the most difficult situations faced by physicians involves strong emotional displays from patients,” (Platt and Keller; Gillotti 1014). Not surprisingly, medical professionals who were recorded delivering bad news as part of the study were perceived as being “not very empathetic” (1019). Gillotti’s study reveals a significant need for revision in communicative practices.

When communication between doctors and patients fails, there are severe consequences that cannot be ignored. And this communication, and those who try to assist in bridging the gap between patient and doctor, is not easy—especially within the rigid structures of Western biomedicine. Ethicist Amy M. VanDyke, who has worked as a consultant within hospitals for years, reports on the pressures that physicians are under in



diagnosing, treating, and releasing patients from the hospital. She writes that, “Physicians and other healthcare professionals occasionally try to impede ethical discussions for a variety of reasons,” and that the attempts to “squelch or divert ethical discussion can come up in many forms, some more difficult to manage than others” (10). Some of these reasons include physicians’ attempts to make decisions on behalf of patients who were without decision-making capacity (10), which would constitute physician’s assumption of the role as a surrogate for the patient. Another reason for preventing ethical discussion between outside experts and patients is that physicians do not want to “slow down the clinical process,” and fear that presenting patients with more options. In a particular experience with a doctor whom VanDyke had a “solid working relationship for years,” she “got an unpleasant response...because an ethics consult was requested” (11).

VanDyke shares: “He made a face at me and said something to the effect of, ‘Great, I guess I will be here for another several hours while you get done doing your ethics stuff. Then I can finally finish up with the patient’s discharge’” (11). What VanDyke saw as her assistance in navigating the divide between doctor’s orders and patient’s needs was rejected by the physician because ethics was “an unwelcome intrusion” in the performance of his job (11). While there are many ethical doctors who seek out additional input in order to more humanely and compassionately perform their jobs, VanDyke’s experience within the hospital setting speaks to the concern over imbalanced power.

### **The Risk of Unclear Hospitality Roles: Memorial Medical Center**

While there are many factors motivating this research, there is one particularly shadowy ethical corner of medical inhospitality that vividly illustrates the importance of

this project and the kinds of ethical dilemmas a more open end-of-life conversation can prevent. In 2009, the *New York Times* published Sheri Fink's, "The Deadly Choices at Memorial," a lengthy study and collection of interviews with healthcare workers, patients, and family members who were at Memorial Medical Center in New Orleans, Louisiana, when Hurricane Katrina hit. During Katrina, Memorial lost power, running water, and was virtually inaccessible due to the height of the waters surrounding it. Temperatures were over 90 degrees, and doctors and nurses worked to evacuate patients as soon as they realized the severity of the storm and the inhabitable conditions within the hospital. However, dozens of patients and a handful of staff remained in the hospital without adequate conditions for days after the hospitals' backup generators stopped working.

In the direct aftermath of the storm, the healthcare professionals working at Memorial were left asking some difficult ethical questions, among them being: "How long should health care workers have to be with patients who may not survive?" (Pou qtd. in Fink). As Fink points out, though, "The story of Memorial Medical Center raises other questions: Which patients should get a share of limited resources, and who decides? What does it mean to do the greatest good for the greatest number, and does that end justify all means?" (Fink). And, perhaps most jarringly, "Where is the line between appropriate comfort and mercy killing?" Mercy killing might be the best description of the events that transpired at Memorial days after the storm—events that, even years later, come to the surface in fragments and fail to present a clear reason why certain choices were made in the face of difficult circumstances. Many of the patients who could not evacuate Memorial Medical Center were part of a particularly vulnerable patient population: most

were elderly, obese, or on some kind of life support. Many were in the hospital's LifeCare wing recovering from surgeries or treatments, but were confined to their beds. In addition to being vulnerable, their conditions at the time of the storm were inconvenient. However, they might not have remained in those states if given the chance to evacuate. When hospital workers realized they needed to leave the hospital, these were the patients who were given lethal doses of medications.

For those in the medical profession, the situation at Memorial is a worst-case scenario, a nightmare of shocking proportions. It presents an occasion where real life and death choices had to be made, and where *healthcare professionals tasked with saving patients' lives could not agree on a singular plan or ethical solution* to their dilemma. In fact, Fink's article reveals just how disparate the opinions of attending physicians were during the crisis. For example, she discusses the testimony of various personnel who saw Dr. Anne Pou bring "numerous vials of morphine to the seventh floor" where patients recovering in the LifeCare wing were given "additional morphine and midazolam—a fast-acting drug used to induce anesthesia before surgery or to sedate patients for medical procedures" (Fink). When healthcare personnel and, in some cases, patients themselves, questioned Dr. Pou's methods, she answered that she was giving them something to "help with...dizziness" or "something to help make you feel better" (Fink). But medical professionals are often especially careful about administering these specific drugs, and particularly because it is well-known that together, these drugs slow patient breathing and can lead to death. Other doctors grew angry at the insinuation that bedridden patients should be given these lethal doses of medications and refused to remain at Memorial, instead venturing out into a city ravaged by flooding, looting, and suffering. Others

stayed, deciding to take part in a “discussion of ‘things that only doctors talk about’” — namely, the euthanization of patients (Fink). These discussions energized some of the sleep-deprived healthcare professionals, who doubled their efforts to help patients up a narrow outdoor staircase and onto the hospital’s helipad in the event that help arrived. Dr. John Thiele stated that at Memorial during Katrina: “The laws of man had broken down, [I] concluded, and only the laws of God applied” (Thiele qtd. in Fink). Toxicology reports revealed that 17 patients at Memorial Health Center received lethal doses of morphine or midazolam, or both. In the years since Katrina, many of the doctors involved in the Memorial Health Center care during the hurricane have retired or moved. Anne Pou was charged with four counts of manslaughter, but was not convicted. Instead, she has become a proponent of increased legislation to protect medical professionals from prosecution if they are faced with difficult ethical decisions during the performance of their jobs.

### **Hospitality Revisited**

Hospitality exists for the protection of all those involved in the interaction. While it could be argued that the healthcare professionals at Memorial Medical Center violated their obligations to act as protective, benevolent hosts toward their guests, it could also be argued that those working within the hospital were themselves held hostage by their responsibility/response-ability towards their patients. Davis uses the term response-ability to define an exposedness that makes response possible; responsibility, then, is what ethics drives individuals to create out of that possibility. Fink reports that some doctors and nurses refused to participate in certain acts, and decided to flee the hospital instead. Applied from this angle, it would seem that the hospitable course of action would have

been to remain present, prevent human rights violations, and assist all patients and healthcare professionals—in essence, seeing the hospitable relationship through to its agreed upon ending. In being able to the situation with one’s full sense of self intact, it seems irresponsible to reject that capability and remove one’s self from the situation. The removal is a rejection of responsibility. As Derrida wrote, “hospitality is opposed to what is nothing other than opposition itself, namely, hostility...The welcomed guest is a stranger treated as a friend or ally, as opposed to the stranger treated as an enemy (friend/enemy, hospitality/hostility)” (4). The relationship between enemy/friend, hospitality/hostility, represents a blurring of the fluid boundary between the two, or what Derrida called “hostipitality.” This confusion, or blurring, is made manifest when host and guest engage in hospitality together; in that simultaneous opening up towards the other, both host and guest open themselves up to the possibility of violence. While the interaction may proceed according to the laws of hospitality, hostility and enmity can seep in and sour an otherwise amicable interaction at any point; they are ever-present. For the healthcare professionals who remained at Memorial Medical Center as the water rose and the power failed, their well-established roles as respected hosts were dramatically altered by the conditions of their crumbling home. They, too, were held hostage by the tragedy. While they may have accelerated the deaths of their patients, their methods were as non-violent as such an intervention could be; the doctors and nurses could not escape the safe haven-turned-living hell of the hospital, but some of their patients could find relief. Their actions may have been taken with their roles of host in mind; a more interesting reading is that they freed their fellow guests from an inhospitable space. Hospitality within contemporary healthcare is more complex than a simple doctor-patient

relationship. There are myriad pressures upon many guests—all with differing conditions places upon them—to successfully fulfill their obligations to the masters of the home. Hospitality governs these interactions, but makes it difficult to locate power with certainty. Think of it this way: all guests (patients, healthcare professionals, loved ones) inhabit different conditional guest positions as they visit the hospital. However, the conditions of their visitation are always subject to change, making their interaction with others unstable. For the healthcare professionals who allegedly hastened patients' deaths, by liberating the most disadvantaged guests from their stay at the hospital, they essentially released those individuals from the conditions of hospitality. But when guests start freeing one another, hospitality is ruptured.

## Chapter Three

### Authenticity in Dying: The ‘Good Death’ of Socrates

*Only this, Socrates, replied Crito:—the attendant who is to give you the poison has been telling me, and he wants me to tell you, that you are not to talk much, talking, he says, increases heat, and this is apt to interfere with the action of the poison; persons who excite themselves are sometimes obliged to take a second or even a third dose.*

*Then, said Socrates, let him mind his business and be prepared to give the poison twice or even thrice if necessary; that is all.*

—Plato, *Phaedo*

*The eyes of others our prisons; their thoughts our cages.*

—Virginia Woolf, “Monday or Tuesday”

Even centuries after his death, Socrates’ influence as one of the founders of Western philosophy can be seen throughout contemporary culture. Robin Waterfield writes that, “Everyone has heard of Socrates, and even if they know little or nothing else about the man, they usually know that he was put to death...The events surrounding Socrates’ death have become iconic—more discussed, portrayed or merely mentioned—than any except those surrounding the death [of Jesus] some four hundred years later” (xi). Traces of Socrates’ legacy shape modern philosophy, teaching, ethics, and law, and in recent decades, Socrates’ status as an icon of philosophical inquiry and rational thought has been co-opted by human rights movements. By conjuring up both the legacy and the intellectual heritage that Socrates is still considered the father of, these groups attempt to align themselves with Socrates’ brand of considered and ethical activism.

One particular movement affiliated itself with Socrates and celebrated him as an embodiment of rationality, not only for how he *lived*, but also because of their interpretation of how he *died*. The group, the Hemlock Society USA, was established in 1980 in Santa Monica, California. Founders Ann Wickett and Derek Humphry chose the

name Hemlock Society because of its connections to “that fellow and poisoner Socrates”; the group even notes that their organization was almost named the Socrates Society (Humphry). They write that they were inspired by the level of choice they see within Socrates’ final days. They claim that, “Socrates’ death...*was a noble and self-chosen one*, and he spent hours discussing with his colleagues whether he should accept the death sentence inflicted by the courts for corrupting the youth of Athens or accept a lonely, barren exile. Essentially, that is what the Hemlock Society was about—*not hasty and hurtful suicide, but thoughtful and rational reasons for an accelerated death*” (Humphry, emphasis my own). In order to reach a wider number of Americans, the group merged with various other end-of-life advocacy groups in 2003 and changed its name to Compassion & Choices. While the group’s “Good Life, Good Death,” motto was abandoned in the merger, what remained were the various groups’ unifying desires to improve end-of-life care and end-of-life options for contemporary patients and to present those (often, not always) medicalized alternatives as rational choice. As William Batt describes, hemlock as a unifying principle remains apt for members of these organizations because, “first...it symbolizes the principle of personal choice central to Socrates’ action,” secondly because, “Socrates faced choices unacceptable to him much like terminally ill people today,” and lastly, “because it focuses centrally on the place of the self in society in a way that was vital to Socrates in his time as well as for living people today” (Batt qtd. in Humphry).

### **The Rationale for Rationality**

However, this chapter will argue that this cultural/scholarly impulse to perpetuate the myth that Socrates was an infallibly rational individual creates problems—chief



among them being that in striving for a Socratic death, individuals are actively seeking an un-rational attitude to threats of personal loss, harm, and suffering—experiences that, in reality, naturally bring up feelings of fear and anxiety. In pursuing a hyper-rational ideal, groups like the Hemlock Society are failing to recognize the divisions between the historical Socrates and the Platonic one, differences that are perhaps more apparent in *Phaedo* than in any of the other dialogues. By prescribing Socrates' death as the best possible scenario for the terminally ill, the Hemlock Society undercuts its own purpose and fails to recognize the other things the *Phaedo* has to say about end-of-life.

There are issues of authorial voice within scholarship on *Phaedo*. “The search for the historical Socrates, like the search for the historical Jesus, continues to generate an even more enormous literature, a vast sea of speculation and learned controversy” (Stone 4). The historical Socrates is a figure patchworked together mostly out of surviving fragments of texts written by two of his students, Xenophon and Plato. The other sources consist of fragments that appear in Ancient Greek, “contemporary portraits of Socrates,” one from Aristophanes' *Clouds*, a play devoted almost solely to Socrates, and “just two generations later,” some “useful glimpse[s] of Socrates” appear in the works of Aristotle (5). It is widely accepted that myth assists in the development of cultures. As Hart and Daughton highlight in their work on cultural criticism, there are a few key types of myths which function within our contemporary culture. Among them are cosmological stories, told to explain “why we are here, where we came from, who are ancestors were,” societal myths, or those which “teach the right way to live...and become more heavily drenched in meaning each time they are told”, and eschatological myths, which “help a people know where they are going, what lies is store for them in the short run as well as the long

run” (Hart and Daughton 243). The works that help the picture of the historical Socrates come into focus meet all of the criteria for myth building. Together, the pieces of Plato and Xenophon’s work help to immortalize the importance of Socrates work, and the works of Aristophanes and Aristotle give that mythology its color. But as with any mythology, the images that readers gain from these artifacts can be imprecise and open to interpretation.

What is widely agreed upon by scholars and historians is that there is no way to truly know Socrates or his thoughts; what we latch onto in Western culture is an amalgamation of various authorial agendas. So, while “we may have a greater number of words about Socrates than about any comparable ancient Athenian...every single word needs to be weighed and treated with caution” (Waterfield xii). When Socrates scholar Gregory Vlastos reinvigorated analytical approaches to classical philosophy during the late twentieth century, he spent a great deal of energy re-classifying the early, middle, and late Socratic dialogues, and noted that, “only a ‘schizophrenic’ could hold such divergent views simultaneously” (Vlastos qtd. in Dillon 551). What Matthew Dillon and other recent scholars of ancient philosophy have deduced is that by the time the *Phaedo* (which falls into the middle dialogues on Vlastos’ timeline) was likely written, Plato would have “matured as a philosopher in his own right, under the influence of thinkers besides Socrates...and that consequently it then becomes impossible to ascribe, with certainty, a given belief to the ‘historical’ Socrates” (526). The divergent views that struck Vlastos as impossible, coupled with the indistinct time of the *Phaedo*’s completion, cast doubt on the possibility of a fully developed understanding of the historical Socrates. After all, Socrates himself wrote nothing until his imprisonment, and

what he wrote was not philosophy but an altogether different project. Instead of writing down his work, he became immortalized by his disciples, many of whom were driven to write by their desire to “exculpate their mentor—to make their fellow Athenians wonder why they had ever condemned him in to death” (Waterfield xi-xii). Take, for example, the significant activities of Socrates’ final day. Socrates, “dying from the feet upwards,” spends his final hours emphasizing to his disciples that, ‘those who truly grasp philosophy pursue the study of nothing else but dying and being dead’” (Dillon 525, Plato 64a). Matthew Dillon writes that, “In the course of explaining this remarkable assertion,” Socrates then “goes on to develop at great length an even more remarkable thesis—remarkable, at any rate, for one of the founding fathers of the Western philosophical tradition: after the death of the body, the immortal soul is reborn according to the merits of its former life, gradually purifying itself as it evolves into pure essence, leaving all corporeality behind” (Dillon 525). Plato is careful to show only a composed Socrates to the very last minute, and reinforces this image of Socrates by contrasting it with the actions of the disciples. In his final moments, Socrates lamented the “loud weeping and complaining” his disciples had broken into, telling them that scene was distasteful and “why I sent the women away...because I’ve heard that one ought to die in peace” (117e). From its first moment until its last, the *Phaedo* represents Socrates as the lone reasonable man in the prison.

The project of the *Phaedo* is noteworthy for a number of reasons. First, the *Phaedo* is in the same vein as other Socratic/Platonic dialogues in that it values reason over emotions or desire. As Halvard J. Fossheim writes, “In our tradition, Socrates, as he figures in the work of Plato, stands for rationality. In one way, of course, the tendency to

treat him as rationality incarnate is not too far off the mark; for Socrates does indeed introduce into our thought and discussions a demand for argument, for stringency and consistency” (851). For many critics, the *Phaedo* stands apart because of its “treatment of desire—desire, that is, for corporeal stimulation or satisfaction. According to the ‘standard’ Platonic account, this sort of desire forms a distinct ‘part’ of the soul, of which another part is reason” (Boys-Stones 4). In the other Platonic accounts, such desire, like reason, could become a “psychological determinant of action” and cause individuals to act either according to reason or in direct contrast to it (4). But in the *Phaedo*, the standard Platonic approach changes in a nuanced way; “Plato appears to be trying something different. According to the Socrates of the *Phaedo*, desire is not of the soul at all, but of the body” (4). In the *Phaedo*, the soul is pure reason, and desire is no longer a *part* of the soul, but located completely in the body instead. This allows for this particular Platonic dialogue to advocate for reason and control over all else *and* to lead readers to believe that the desires plaguing the soul and preventing reason could be left behind in death. Despite the *Phaedo*’s difference, throughout the Platonic dialogues, “reason is capable of maintaining control—in the first place precisely by avoiding situations of intense pleasure and pain which might impede its own activity” (Boys-Stones 8, Plato 83b). But Fossheim argues that Socrates often engaged in activities that could be labeled irrational. He claims that, “the manner in which Socrates carries out his historically influential elenctic activity belies the shortcomings of this oft-quoted and inspirational picture” of the purely rational Socrates (851). In a particularly persuasive passage, Fossheim paints philosophical engagements with Socrates as interactions which promised the risk or reward of pleasure or pain. He describes Socrates’ “refutational dialectic” as

“painful,” and writes that, “Taking a dialectical beating from Socrates demands of you that you actively decide to enter a game which might take hours. Not least, it requires that you stay alert and engaged, that you remain willing to play—and to play by Socrates’ rules” (852). This description of Socrates’ philosophical inquiries as an arena of conditions echoes the rules of engagement in hospitable relationships. In philosophical engagement as in hospitality, both parties have ‘skin in the game’; the extent to which the risks are taken and the point at which payoff occurs, though, is in the control of the host who, claiming ignorance, knows all the questions and their answers.

It is crucial to note that the *Phaedo* depicts the death of Socrates as an almost constant struggle between the very same intense experiences of pleasure and pain that Socrates/Plato warn might cause a true philosopher’s grip on reason to fail. In relaying the story of Socrates’ death, *Phaedo* tells Echechrates that “it was simply a strange experience: an unusual combination of pleasure mixed with pain at the thought that he was soon to die. Everyone there felt much the same. Now we would laugh and sometimes we’d cry” (59a). This connection between pleasure and pain, enchainment and release, is an echo of Socrates’ own statements on the day of his death. As *Phaedo* relays, when his friends arrive in his cell on the day of his execution, Socrates is seated and soothing an area on his body where his chains have just been removed. He greets his visitors, (who enter to find him “rubbing and bending his leg),” by stating, “How strange, gentlemen, is this thing people call pleasure! How strangely related to its seeming opposite, pain: They refuse to occur in a man together, yet if you pursue and capture the one, you’re nearly always forced to take the other, too, as though they shared a single head” (Plato 60b). Socrates then continues, commenting on the pleasure-pain relationship that if, “Aesop

had noticed them, I think he'd have composed a fable" (60b). Within the first pages of the text, Plato has created a correlation between the dynamic of *physical* pleasure-pain and *emotional* physical-pain; that correlation is largely based on the experience of the Mobius-like pleasure and pain as *strange*—simultaneously foreign and familiar. In a text that seemingly advocates for reason and a rational approach to dying, Plato's *Phaedo* illuminates the two experiences which can undo reason—intense pleasure and/or pain—and gives them starring roles in the dramatic retelling of the death of Socrates.

### **Why Socrates?**

When he was found guilty of impiety and corrupting Athenian youth in 399 B.C.E., Socrates was 69 or 70 years old. Upon receiving the verdict, he asked the jury of 500 of his fellow Athenian citizens to release him so that he could return to his life's work. Instead, they condemned him to death by hemlock, a standard method of execution in Ancient Greece. But Socrates' sentence was not carried out immediately. Instead, his existence was suspended between life and death for nearly a month while he waited for events outside of his control to transpire. The events controlling his fate would have been familiar to ancient readers, but are worthy of some summarization here.

Ancient Greeks were wary of executing citizens during festivals that honored the gods. Socrates' sentence was handed down at the start of a festival honoring Apollo. During the festival, a sacred ship sailed from Athens, around the island of Delos, and back to Athens in commemoration of the journey that had carried Theseus to Crete when he killed the Minotaur. According to Ancient Greek mythology, prior to Theseus' actions, each year the city of Athens sent fourteen teenagers, seven girls and seven boys, to Crete as sacrifices to the Minotaur living within the island's labyrinth. In order to free

the city from its obligatory human sacrifices, Theseus and a few of his soldiers stowed away on the ship and when they landed in Crete, they slayed the minotaur. Plato writes that, “after a voyage begins, the city must be kept pure and no one can be executed until the ship has reached its destination and returns” (Plato 53). This particular voyage was of great cultural importance to the Athenian citizens and to The Eleven, a group of officials tasked with Socrates’ imprisonment and execution; as such, the custom of waiting until the ship’s return was honored. As fate would have it, Socrates “lingered in prison for thirty days, awaiting the return of the official Athenian ship from the festival (it set off for Delos the day before his trial and its return was delayed by adverse winds). Apollo, the god to whom Socrates felt the closest, was looking after him to the last” (Waterfield 6). In Athens at that time, though, “Imprisonment was not, as now, a common punishment,” and so “prisons were used less as places of long-term internment than as temporary holding-stations” (6). If Plato’s/Phaedo’s account of Socrates’ imprisonment is to be believed, he spent his final month “conversing with friends and family members” and making his only known attempts at writing (in the form of poems, or songs) (6).

Prior to his imprisonment, Socrates had often found himself in disadvantaged positions. This was due, at least in part, to his fundamental disagreements with how Athenians lived and which pursuits they spent their time on. Aristotle would later write that “a cityless man is ‘like a solitary piece in checkers’” (Stone 98). Since meaning is only derived when the game pieces are seen alongside their counterparts, Aristotle’s meaning is clear: people have value when they are members of something larger than themselves. For ancient Greeks, this meant the *polis*. But for Socrates, this endeavor was foolish; instead, “Socrates preached and practiced withdrawal from the political life of

the city” and declared his absence “necessary for ‘the perfection’ of the soul” (98). When we consider the greater context, we see that “the conflict between Socrates and his native city began because he differed so profoundly from most of his fellow Athenians and, indeed, from the ancient Greeks generally, on the basic philosophical question of the nature of the human community. In essence, Socrates’ pedagogical project was a rejection of the mission of the *polis* (Stone 9-15). In the Athenian *polis*, citizens governed themselves. Socrates advocated, instead, for a government that was “ruled by experts” (12). In Xenophon’s Socratic dialogues, Socrates “went on to show,” that “on a ship the one who knows, rules, and the owner [of the ship] and all the others [on board] obey the one who knows” (*Memorabilia*). Additionally, the “classic ideal was to perfect oneself in perfecting the city” (Stone 115); however, in the *Apology*, Plato’s Socrates tells his accusers that, “I go about doing nothing else than urging you, young and old, not to care for your bodies but for the protection of your souls” (qtd. in Stone 115). In their attempts to forge a democracy, Socrates seems to have been worried that Athenians had lost sight of the real purpose of living. Through his practices in philosophy, he promoted an alternative to the *polis* by fostering a carefully curated inner circle and life—in which he strove for expertise through philosophical practice, and consorted closely with others who had been persuaded by his approach *and* who were dedicated to their own philosophical pursuits—often trying to unravel Athenian democracy in the process (Waterfield). However noble his initial purpose might have been, as a guest within Athens and a citizen beholden to the sovereignty of the Athenian city-state, Socrates was quick to criticize and irritate his hosts. Additionally, he was quick to instigate mutinies among his fellow guests—a crime that he was eventually convicted of.



His methods aside, Socrates disagreed with the methods used by Athenians in constructing their society and building the *polis* as well as the very constructs they had developed to rule themselves. These power dynamics seemed problematic to him; despite what Socrates considered their lack of practicality, they were particularly useful in allowing Socrates to develop a meaningful morality of his own. In the dialogues, Socrates is often seen using his self-proclaimed *lack* of knowledge to establish his position as a subject. In the case of his trial and conviction, for example, Socrates asks “for hospitality in a language which by definition is not his own, the one imposed on him by the master of the house, the host...the nation...etc. This personage imposes on him translation into their own language, and that’s the first act of violence” (15). Derrida recounts in the first pages of *Of Hospitality* that within Plato’s *Statesman*, “Socrates’ first words, from the first sentence of the dialogue, are to thank Theodorus for having introduced him...but also, at the same time,” to invoke the notion of the foreigner and the accompanying laws of hospitality (11). Derrida elaborates, citing that in *The Apology of Socrates*, Socrates “declares that he is ‘foreign’ to the language of the courts...he doesn’t know how to speak this courtroom language...he doesn’t have the skill, he is *like* a foreigner” (15). I argue instead that Socrates develops this strategy for dealing with difficult dynamics of power. By repeatedly invoking his status as foreigner and requesting the protections and allowances given to foreigners in ancient Athens, he was intent on reminding his audience that he was not the expert here. However, his deftness at finding and, in many cases, exploiting these disadvantageous social and political positions calls his lack of expertise into question. Consider Socrates’ use of the metaphors of enslavement. In “The Manumission of Socrates: A Rereading of Plato’s *Phaedo*,” Deborah Kamen aligns

Socrates' death with manumission, which is the release of slaves from slavery. She draws a distinction between Plato's descriptions of "good slavery" and "bad slavery", writing that in *Phaedo* and other places, "Socrates declares that if the better elements of one's mind prevail, they enslave that which causes evil in the soul and 'set free' that which causes virtue" (89). Additionally, "in the *Republic*, Socrates says that in a man who has committed an injustice and been appropriately punished, the beastly part of his is tamed and the gentle part 'set free'" (*Republic* 591b qtd. in Kamen 89). Socrates, despite his desire to align himself with these plighted groups, was neither a slave nor a foreigner in Athens. Socrates had been proclaimed the wisest man that had ever lived. It is difficult to believe that, on occasions when he admitted ignorance, his fellow citizens did not find it interesting and worth listening to—which I argue is a powerful move on the part of the (apparently unwilling) rhetor Socrates. On occasions where Socrates claimed ignorance or foreigner status, the common thread running through the manipulations of power is this: guest-host relations both require that one party submit to the will of another—particularly in order to survive and to gain agency. But with agency comes the potential for violence. In opening himself up to the citizens of Athens, Socrates opened himself up to the possibility of violence from not one, but 500, disappointed hosts. This openness was ultimately part of his undoing. As the rest of this chapter will show, it is too simplistic to read Socrates' actions and recorded conversations as pure reason. The motivations to have the discussions, the manner in which they are carried out, and the continuous and arguably insatiable need to open towards the other are more than reason: they are rooted in strong emotion—passion, even.

In this chapter I argue that the Socrates of the *Phaedo* has been misunderstood and his death misconstrued. For decades, his death has been treated as one of rational choice rather than taking the facts into consideration. The death was a state-sanctioned execution. It was also, in some way, a suicide. Despite the vague nature of his death, Socrates' end-of-life has been celebrated as an example of the "good" way to die; this chapter will show that this particular view is too narrow. Instead, Socrates' death can illuminate the end-of-life debate in America, but not because of the 'singular rational choice' celebrated by the Hemlock Society. Rather, Socrates' death can be read as a coming-to-terms; in his final days, Socrates experienced anxiety that catalyzed final efforts to make amends. His death, then, is less about rationality than about securing a future immortality for his soul and encouraging his disciples to do the same. Suspended between life and death and confined to a prison cell, Socrates made attempts to right past wrongs, glorify the gods, and leave his loved ones with final lessons on how to attain peace. One of the key factors influencing our idealization of Socrates' death is the perception of his control over his own life's uncontrollable forces, especially in the face of his unfortunate circumstances. But for too long in these interpretations, Socrates' control over his attitude and language has been conflated with control over his actions. Additionally, I argue that his conversations with friends at the end of his life, as depicted in Plato's *Phaedo*, illustrate the impossibility of complete *being-towards-death*. As this chapter will show, it is crucial to explore the distinction between a self-chosen death and acceptance of a government-sanctioned one. While Socrates may have experienced a lifetime of openness to *being-for* the other and striving towards reason, death's limitations make *being-toward-death* in a rational way an absolute kind of hospitality, a

violence without boundaries or defense, and an impossibility. Rather than treating his death as a self-chosen one, this chapter argues that in the *Phaedo*, Socrates had given up his habits as the city gadfly and was instead working within the standards of hospitality. While imprisoned, Socrates more fully inhabited the role of the dutiful guest. He did not try to escape, by all accounts he was gracious towards his captors and they were even mournful of his passing. His motivations at the end-of-life read less like a rational embrace of the inevitable, and more like someone who, given limited time to remedy wrongs, is suddenly energized by the anxiety of the unknown.

### **Socratic Anxiety**

The tension within *Phaedo* stems from the waiting. With Socrates' execution held up until the arrival of the ship from Delos, Socrates was a powerless captive. His friends and family, too, co-existed with his death looming over them—making the day-to-day interactions strange (59a). (Just imagine how different and how much less natural your interactions with others would be today if you knew they may die tomorrow?) This strangeness rendered Socrates a member of the *living dying*, individuals who know their death is *almost* here, but can do nothing to hasten or prevent it. This in-between is where today's terminally ill individuals fall, too; they may still be alive, but post-diagnosis, they inhabit a very different reality than they did pre-diagnosis. While he awaited his death, Socrates' position as a *dead man talking* would have been obvious to his friends and Athenian citizens.

Given a month to live in an unfamiliar house with less than generous hosts, Socrates was fueled by a productive kind of anxious energy. In *Phaedo*, Socrates shares with his visitors that his days in prison have been spent composing music, or demotic

poetry, out of Aesop's fables. After having dreams and visions urging him to compose music for years, in his final days, Socrates became worried that his lifelong practice of philosophy, which he regarded as the "greatest music," was not what the muses/gods had actually meant (60e). In order to please Apollo, the god whose festival had delayed his execution (and a god that many scholars claim Socrates had a special connection with), he made music—first a song in tribute to the god, then music out of fables because he "knew them by heart" (61b). Consider these endeavors through the lens of hospitality: it is as though when confronted with death, Socrates realized that he might have been ignoring the wishes of his ultimate host for years. If prison was a house of sorts for Socrates, it was always one with a limited stay. In reflecting on his life, Socrates seems to have recognized that the gods were his hosts all along and that his body was the house he inhabited at their pleasure. He even suggests as much when discussing bravery and goodness with Cebes. Socrates suggests that "initiations," or mystery religions might "not be completely inept, but were hinting all along that whoever gets to Hades uninitiated and imperfected will lie in mud, whereas the purified and initiated will live with gods" (69c). Socrates tells Cebes and the others that these men who believe in the sanctity of the perfected soul and its immortality are "proper philosophers" and, "in my life I've left nothing in my power undone but have been in every way eager to join them" (69d). In this part of the conversation, Socrates' commitment to his status as pure philosopher is fluid: he moves between being ready for death and seeing it as the highest achievement for real philosophers and anxiously attempting to complete final tasks before he dies. But in the same breath that he declares that he has left nothing undone, he states, "Whether my eagerness has been properly placed and we've accomplished anything, we'll know

clearly, god willing, when we get over there; quite soon, I imagine” (69d). If Socrates did think that he had accomplished all of his earthly tasks and fully purified his reason-soul for its impending exit from its desire tainted body, then why waste time and effort on composing songs? I argue that he expends energy trying to remedy this grievance—this refusal—that he may have made against the gods while he was still a guest out of fear. Socrates dedicates himself to the task, describing his efforts as “obedience to the dream” (61b). These acts of obedience—as a citizen of Athens and as a temporary guest within the prison—stem from the intense fear. When faced with death, Socrates’ wisdom and reason could not provide him with a certainty over his fate. Instead, out of control over his circumstances, he busied himself with tasks that he hoped would gain favor with whatever beings did have the control. Therefore, since Socrates believed that the most likely hosts were the gods, he appealed to them through song.

Anxiety manifests in myriad ways, but it is deeply individualistic. In *Being and Time*, Martin Heidegger reignited critical interest in the concept of *being*. In the book’s opening pages, he claims that, “The question” of *being* “has today been forgotten,” despite the fact that the question “is hardly an arbitrary one” (1). Instead of being arbitrary, the question of *being* it is the very question which “sustained the avid research of Plato and Aristotle but from then on ceased to be heard *as a thematic question of actual investigation*” (1). In order to understand anxiety, then, it is necessary to consider *being* and how one might come-to-terms with larger anxiety-inducing existential questions—especially when confronted with the closeness of one’s *un-being*. *Being*, for Heidegger, is actually the most important focus of philosophical inquiry—and the most elusive one, since “being is always the being of the being,” (8). Heidegger calls the

essence of being *being*, but human existence becomes *Dasein* (which in German translates to ‘presence’), an experiential kind of being that is “*made* known to the understanding of being that belongs to *Dasein* itself” by peering through the “basic structures of the very being of *Dasein*” itself (38). *Dasein*, in which “the essence of being lies in its to be,” which is its *has* to be (39), is, therefore, the *being* that “is the transcendence, plain and simple” (34). The transcendence of *being* to *Dasein* is “distinctive” transcendence “since in it lies the possibility and necessity of the most radical *individuation*. Every disclosure of being as the transcendence is transcendental knowledge” (34).

For Heidegger, the question of *being-in-the-world* requires work on the part of the *Dasein*. The *Dasein* must exist in the world, “this world that is always already from the outset my own,” and understand itself as separate from others so as to ascertain the purpose and usefulness of others in the inevitable event of an encounter (Heidegger 118). But Heidegger cautions that, “the characteristic of encountering the *others* is, after all, oriented towards one’s own *Dasein*. Does it not, too, start with the distinction and isolation of the ‘I,’ so that a transition from the isolated subject to the others must then be sought?” (118). But rather than emphasizing difference, the necessity of distinguishing between one’s own *Dasein* and others is done in recognition that “they are, rather, those from whom one mostly does *not* distinguish oneself, those among whom one is, too. This being-there-too with them...the ‘with’ is of the character of the *Dasein*, the ‘also’ means the sameness of being as circumspect, heedful being-in-the-world. ‘With’ and ‘also’ are understood *existentially*, not categorically” (111). Davis latches onto this definition of *Dasein* when discussing belongingness in a hospitality context. She writes: “Heidegger is

clear that *Dasein* names (a) being that is first of all in-the-world and with-others—‘world’...being always a ‘shared world’” (90). Heidegger defined *Dasein* as a more specific state of belonging in the world; *Dasein* is “first of all an intrinsic part of the world, though it becomes ontological through its primary and unique concern with its own identity” (Blackwell 3). The time necessary to such self-awareness is obviously most crucially perceived in the advent of one’s own death. *The fact of dying for and by ourselves is what gives the self authenticity, making it a ‘being-toward-death’*” (3, emphasis my own). Recognition of otherness is also recognition of the similarities between the self and all others, and as such, a recognition of the separateness—and the possibility of the outer limits—of the self. Put plainly, individuals share the world with countless others who, through their existence and interactions with one another, add definition and a sense of singularity. It is in this close proximity to others that we recognize death, and this recognition of death pushes us to “reach absolute authenticity in an ecstatic being-toward-death,” revealing “less a sense of alterity than the area in which I come into what is absolutely and precisely mine, mineness” (3).

The notion of *being-towards-death* requires that one overcome anxiety that arises in the face of death. Anxiety is a force that is indefinable, but also all around. It supplants the *Dasein*’s self control with “radically generalized fear, fear for one’s own being, one’s own being-able-to-Be, and the suffocating force that oppresses *Dasein* in anxiety turns out to be *Dasein* itself, calling in as the voice of conscience from its future authenticity” (Davis 92). Anxiety’s greatest power is this disruption of the self’s control over itself. Once *Dasein* recognizes that it is not in control, anxiety overwhelms it. At the point of realization of anxiety, the *Dasein* is not capable of locating and strengthening its own



boundaries; boundaries wouldn't do, anyway, since the anxiety is wholly contained within the *Dasein*. Anxiety is the recognition of the “*not-at-home*” (Davis 94). In this state of unwelcome, the *Dasein* that is “nostalgic for the comfort and safety of what it thought was home,” (94), typically takes “flight” (Heidegger 184), “scrambling towards an ‘at home’” (Davis 94). Heidegger states of this flight: “existentially the authenticity of being a self is closed off and repressed in entanglement, but this closing off is only the *privation* of a disclosedness which reveals itself phenomenally in the fact that the flight of the *Dasein* is a flight *from* itself. That which *Dasein* flees is precisely what *Dasein* comes up ‘behind’” (185). This fleeing and seeing is only possible because of the disclosedness of the *Dasein*; the *Dasein* is the only singularity that can truly know itself. The turning away enables the *Dasein* to “grasp” what it is fleeing from—essentially, the turning away of the *Dasein* from itself enables it to come self-to-self with itself within the safety of its closedness. Anxiety is the thing that can be grasped in these encounters, since in turning away from its finitude and its angst over its limitations, the *Dasein* can come up behind the fear and grab a hold of it to gain a closer look. This experience is not devoid of reason; given the introspection that Socrates was certainly doing during his final month of life, the grappling with the self that Heidegger so succinctly captures in his discussion of *Dasein* seems completely reasonable. It is that *Dasein*'s approach to being-toward-death that creates an even stronger case for Socrates' possible anxiety at his end-of-life.

As Davis writes, “*being-toward-death* is a mode of being in which *anxious Dasein* gets its mortality in its sites in an understanding way and so achieves power over it—Heidegger's definition of understanding, it should be noted, is ‘being-able’” (95). It

could be said that this power, this *being-toward-death*, provides those who achieve it with agency at the end of their lives. But some, Levinas among them, challenge the notion that being-able somehow gives one power over one's anxiety about death. Christopher Fynsk writes that in thinking that death can be confronted and fully accepted, "We glimpse here one of the oldest ruses of philosophy, an appropriation of the very event of disappropriation, an overcoming of the most radical form of otherness and negativity in the essentially tragic gesture of confronting death. Death has become a possibility" (Fynsk 38). Fully *experiencing* one's own death is the impossibility, but accepting one's death as fact, as realistic and inescapable option, is the "*the possibility that opens [Dasein] to all other possibilities*" (Davis 94). Making death a possibility makes it strange and does not mean that the individual or *Dasein* has successfully gained control over anxiety. It simply means that, for better or worse, the *Dasein* has distanced itself from the certainty of death by recognizing and grabbing a hold of its angst.

In reading Socrates' death through this lens, the dance between the philosopher and anxiety comes into focus. Socrates' claims vacillate between reassuring his friends that he is fine with dying—that he "lightly and cheerfully" downs the poison, even (117c)—and attempting to spin his death into an enlightened release of the soul from the prison of the body. For example, he urges his followers, if they are sensible, to "follow me as quick" as they can to their deaths (61c). He claims that his friends, will "be willing, like any decent philosopher" to die, though it might be unwise to "use force on himself" since "they say that's unlawful" (61d). The illegality of suicide is then considered when Socrates states:

Though perhaps it will surprise you if, of all things, this alone is absolute: if, unlike everything else for man, it never turns out to be better for some people to

die than to live; and it may also surprise you that it's impious for these people—who would be better off dead—to do themselves the favor, and they have to wait for some benefactor to do it for them. (62a)

This must have been a difficult truth for Socrates' friends, individuals who had planned an escape and exile for Socrates at the time of his sentencing, to accept. But Socrates, accused of breaking the law and corrupting his home's young people, chose to go through with his execution. There are numerous opinions on why Socrates might have done this; some suspect that by following through with his sentencing, Socrates was trying to display his strong sense of duty and citizenship and his love for Athens; others think that his death allowed him an opportunity to continue his argument with the Athenians who had accused him—that in dying nobly, he was not allowing them the satisfaction of his confession or guilt. But these opinions still fall short of capturing the gravity of Socrates' decision, and his motivations. Instead, I argue that within *Phaedo*, Socrates employs his rhetorical skills in order to alleviate the tension in those around him (and the guilt that the living will feel), but more so in order to assuage the anxiety that his death brought about in him. By reading Socrates' final dialogue as one final rhetorical strategy, the power of *Phaedo*, and its possible power for the contemporary end-of-life movement, can be illuminated.

### **An Alternate Ending**

In an attempt to de-mythologize Socrates' death, I offer a re-reading of his ending with the notion of anxiety in mind. Throughout his teachings, trial, and imprisonment, Socrates made it clear that he was willing to die for what he believed. The foundation of Socrates' work was his perpetuation of the belief that through his knowledge, wisdom, and the pursuit of the good, he could correctly and fully ascertain truth. When his

audience gathers just hours before his death, Socrates embarks on a conversation/lesson full of his trademark rhetorical moves: questioning, leading his audience to answers, and doling out wisdom. As the guest who is about to be executed, his hosts have given him some leeway, and he takes full advantage of it, providing his audience with a remarkable set of final thoughts to ponder and take comfort in. In order to successfully show his mastery over death and convince his audience that his approach was the correct one, a great deal of time is spent in discussion of the body's evils. For the *Phaedo*'s Socrates, the body is the boundary keeping the soul from realizing its full potential—which is to grasp the truth and to fill the soul with reason. He suggests that the soul cannot “seize truth” in life (65c) because of the body's lack of purity, stating that, “When body and soul are together, nature directs the body to be ruled as a slave, the soul to rule as the master. So going by that, which do you think is more like the divine and which like the mortal?” (80a). When Cebes and others agree that according to this claim from Socrates, it follows that the soul must be immortal, Socrates agrees. Burger points to this point in the discussion as a turn in Socrates' purpose because he begins to make efforts to persuade his audience that “there is something or the dead and, as it is said of old, something better for the good than for the bad” (63c). She claims, “It is to such a hope—which has hardly been confirmed in the preceding series of arguments—that Socrates now returns” (189). Socrates tells them that they are right, and that, “the soul is most like the divine, immortal, intelligible, single-formed, indissoluble, and the ever selfsame in every respect” (80b). Bodies greatly limit the individual's attainment of peace and knowledge, since “the body and its necessary upkeep presents endless distractions, and if we fall prey to disease, that, too, hinders that hunt for what *is*...Because of our bodies, we can't even

hear ourselves think” (66c), and also because bodies “shrivel”, decay, “collapse” and suffer (80c-d). John Sallis writes that in his attempts to discuss the meaninglessness of the human body and its removal of the soul from a place of knowledge, Socrates purposely aligns “the figure of philosophy with that of death” (370). Socrates tells his friends that when the soul attempts to “touch the truth,” or when it “attempts to look at something along with the body, it’s clear that then it’s deceived by the body” (65b). This is how death becomes the release of the soul. Enlightenment can only be realized if the body is no longer blocking the soul’s strivings.

But there are flaws in this line of thinking, mainly stemming from an unresolved anxiety over the possibility of one’s finitude. I read the pleasure and pain of Socrates friends-turned-mourners as this anxiety made manifest. Whitehead suggests that rather than being shocked by Socrates’ sentencing and reasonable approach to death, his followers and friends would have realized that the philosopher had “been living on borrowed time ever since the defeat of the Thirty in 403” (193). They could not have been caught too off guard since for years, “there had been dark mutterings about the influence of Socrates over the baneful characters” like Alcibiades and Critias and the oligarchic set of the 420s and 410s who had been educated in large part by Socrates (194). Whitehead also suggests that as a figurehead who chose to remain in Athens when things were going terribly wrong with his students in positions of power, Socrates had opened himself up to prosecution. In an Athenian society that was invested in maintaining democracy, prosecution was only the next logical step. If Socrates had wanted to avoid prosecution or execution, he would have done left the city sooner.

With this in mind, Sallis suggests that some of Socrates' claims about the body as boundary are actually intended to be comic relief, or are attempts by Socrates to lighten the heavy atmosphere surrounding his death. Perhaps it is possible that his followers understood the very reasons why he was not only prosecuted, but sentenced to death, and needed to be made to understand why Socrates had not chosen to save his life by leaving earlier. At any rate, Sallis hypothesizes that in *Phaedo*, Socrates might be trying to relieve his followers of *their* anxiety, especially when he leads them to pretty dire conclusions. For example, when his fellow 'true-born philosophers' work themselves up to the frenzied realization that, "in our considered opinion, if we're ever to have clean knowledge of anything we must get rid of the body and observe the things themselves with the soul itself. Then, it seems, we'll have our desire and what we say we love: knowledge—when we die, not while we live" (66e). If, as Sallis suggests, it is meant to illicit laughter, then the joke is part gallows' humor and part trickery. Socrates suggests that his friends develop a longing for death, follow him quickly to it, and look forward to a time when their souls will be able to examine truth more fully. Sallis clarifies his reading of death-philosophy-as-joke, pointing out how often *Phaedo* mentions Socrates' grounded position—feet firmly planted on the ground, connected to the earth, prepared to give his body over to it. This is perhaps because, as Socrates alludes to later in *Phaedo*, there is no way of knowing what happens to the soul upon death. Rightfully so, some may "fear that when the soul leaves the body, it perishes and is destroyed and...released from the body, instantly flies away and scatters like wind or smoke and no longer exists anywhere" (70a).

Here is the risk involved for Socrates: If he gives into anxiety and fear about death, if he acknowledges that the soul might not be an immortal entity that can achieve enlightenment once it is, “freed from wandering and folly, from fears, from cruel passions, and all other human evils” and can “truly spend all future time with the gods” (80e), then what is the purpose of life? This would only call into question his entire life’s work, and would destabilize, or create anxiety within, the knowledge and enlightenment that he has been guiding his followers towards. Instead, Socrates tells his friends that a philosophically inclined soul “departs pure, dragging with it nothing of the body because in life it never willingly partnered with it, but fled the body and gathered itself to itself as its constant practice—which is precisely the right philosophy and the true practice of facing death lightly” (80e). Souls that unsuccessfully maintain their separation from the body “depart defiled and uncleansed of the body because it always consorted with it, loved it, catered to it” and are “patched with corporality” (81b-c). Socrates urges his audience to imagine these threadbare souls as “weighty, earthly, heavy, and visible, so that such souls are dragged back to the visible region by the fear of Hades and the invisible”, where their souls are also likely to wind up incarnating the bodies of lesser beings; or worse, where they end up haunting the living (81d-e).

There are a number of possible motivations for the dialogue that transpires in *Phaedo*. As mentioned previously, Plato and others have used Socrates to create a mythos of rationality. The “distinction Socrates presents in reflecting on the status of his mythos, addressed to a man with sense, should be no more surprising than his separation of the pious, whose reward has been described most beautifully, from the philosopher, whose fate after death has been shrouded in silence” (205). Within this mythos, one of Socrates’

motivations might be alleviating the feelings of guilt and sadness that his friends are having difficulty hiding. He might be trying to get them to accompany him in his leap of faith. And, he also might be attempting to gain control over a narrative and over the perceptions of a group of people because such mechanisms of control have long been his sources of power. Rather than allowing death to render impotent his life's work, Socrates uses the position(s) of the condemned, the enslaved soul, and the guest, in order to regain agency.

As evidence of Socrates' human reaction to death, consider the heightened activity that took place when Socrates' final day was drawing to a close. When Crito mentions in 63d-e that the executioner needs Socrates to be calmer in order for the hemlock to work, Socrates tells him to "Forget it," and have the executioner "make enough for two or three times what's needed" (63e). Rather than strictly adhering to his captor's wishes, then, Socrates pushes the limits so that he can calm himself through philosophical discussion—a field that he was completely at home within. I read this as Socrates at a moment of high-anxiety; with the eyes of his followers upon him, he cannot refute the seriousness of his situation. But he can distance himself from confronting his mortality, he can make them all marvel at his intellect, and he can carve out a familiar home within the final hours of his life. When it came time for his execution, Socrates allegedly "drained the cup in one breath" (117c), perhaps because of the purity of his soul and the certainty of his convictions, but also perhaps because of a completely normal desire to relieve the sense of not being at home, the sense of not having a place. At the time, hemlock was not the standard method of execution (Waterfield 7). Hemlock as a form of "execution had been introduced only a few years earlier, and had not yet replaced



the most common method (a kind of crucifixion), perhaps because it was considered expensive; at any rate, the preparation of the dose was paid for by friends or relatives of the condemned criminal rather than by that state” (7). While it used to be considered a particularly “painful and ugly” death “with spasms, choking and vomiting...we now know...that the particular species used for this purpose in ancient Athens was effective, but not especially violent” (8). So in paying for the dose of hemlock, what Socrates’ benefactors were really purchasing was “a more benign death for their friend” and a death that “freed the state from the miasma of guilt” because it was bloodless and self-administered (7).

### **Good Death?**

Plato’s depiction of Socrates as calm in the face of death is complicated by the actions that Socrates is shown to take part in. Levinas writes that death is “absolutely unknowable...foreign to all light, rendering every assumption of possibility impossible, but where we ourselves are seized” (*OTB* 71). Davis builds upon Levinas’ work, writing that, “According to Levinas, death *un-powers* me and is in *no* case mine—even when it’s ‘mine,’ even when it’s happening to ‘me’” (97). This unknowability only emphasizes the lack of control that the dying—*any* dying, *all* dying—experience upon their deaths. The death of Socrates was marginally unique in that it did not happen suddenly or by accident. His death sentence was intentional, as was his forced waiting. And in that waiting, he was given a gift that few dying people are given: conditional hospitality, access to friends and family, and an opportunity to follow the urgings of his soul up until the very end. While those actions may have quieted his anxiety and assisted in his sense of control, they did nothing to enlighten him to what dying was going to be like. And,

they did not guarantee that he was correct about the nature of dying. Instead, *Phaedo* is offered up as a text of consolation, as a call of warmth, to those who lost their friend and teacher. Heidegger writes that the call, “does not come from someone else who is with me in the world. The call comes *from me and yet from beyond and over me*” (BT 320).

In reality, Socrates’ circumstances presented a giving-over of the *Dasein* and a kind of *impossible* choice rather than a *rational* one. It is impossible to know one’s own death, and therefore impossible to approach it with clear-headed rationality without having intense feelings come about. All that one can truly say is that this death is a certainty, a completion of the entire experience of *Dasein*. One can only rationally accept that one has no idea what will happen upon death, and then endure the anxiety that accompanies such a realization. Approaching death with this attitude might be more persuasive to those for whom the anxiety of *being-towards-death* is significant. For many individuals who, with good reason, experience anxiety when considering their deaths, this purely rational approach is alienating. The rationality is strange—which is why it is represented as such in *Phaedo*. For those struck by the strangeness, the cheerful extinguishing of the life by an individual who ‘drains the cup in one breath’ raises concern. Critics of aid-in-dying worry over the legitimacy of a person’s rational thought when suicide is their desired option, a debate elucidated in chapters 3 & 4. While “Western society allows people to undertake risk or harm to some degree without intervention,” accepting one’s death is one thing (Wasson and Cook). Becoming a cheerful agent of one’s own death is another.

In the final passages of *Phaedo*, Phaedo tells Echecrates, “I was so overcome that I burst into tears, buried my face in my cloak, *and wept for myself—not for him*, but for

my own misfortune at losing a companion like him...no one could keep from breaking down except Socrates himself” (117d, emphasis my own). In this particularly vulnerable situation, tears are wept not for the dying, but for the living. Davis writes, “I am a subject to the precise extent that the ungraspable Other has already inspired ‘me’ in the most fundamental sense...Even my generosity does not come from me...but amounts instead to ‘a command performance issued by some unknown force that I can only welcome’” (Davis 108). Throughout all of our interactions in life, the unknown force of the Other calls us to act, to perform our version of ourselves at that moment, and we respond to that call. Socrates performs the ‘good death’ that his audience commands because of this call. For the audience, their presence is not intended as comfort, but as one final opportunity to lay claim on Socrates the friend, teacher, and condemned. Their presence is less about him and, as Phaedo admits, more about their own grappling with his loss and their lost ability to inspire him to provide them with the version of him that they desire. Levinas describes this call as a “claim laid on the same by the other in the core of myself, the extreme tension of the command exercised by the other in me over me, a traumatic hold...which does not give the same time to await the other” (*OTB* 141). Although we live our own lives, we are constituted by and in our relationships with the other. And, in our deaths, we perform the final acts of our Being and the required acts of generosity for the others who remain when we are gone.

In trying to situate this chapter’s more nuanced version of Socrates’ death within the contemporary debate over end-of-life, it is necessary to look at the impacts of that death. For those present inside the prison cell with Socrates, the emotional impact of watching their friend die was overwhelming. If we consider our contemporary sentiments

towards death, it seems likely that Socrates' friends wanted to believe that his death was one of rational choice because it suited their image of him—and perpetuated that image to the masses. It comforted them to consider that Socrates died in a fashion that was similar to how he lived, and therefore 'authentic' in some way. If this is true (or at least closer to the truth), then Socrates' attitude at the end of his life was largely for the benefit of his audience. When we witness death, we do not weep for the unknown that the dying individual is going into because we cannot possibly understand what that place or state of being is. Like Phaedo and the others present at Socrates' death, we emote for ourselves, and because of the strangeness of the experience. Death is foreign, but in its foreignness, it forces our *Dasein* into flight and into an existential predicament. So while we mourn the absence of the dying individual, we also mourn the rupture of our own ignorance of death. Once death has been witnessed, we can no longer deny its existence and we are held captive by our anxieties. Whether or not he achieved community with the gods upon his death, Socrates was freed in death. But what he was freed from were the entanglements of citizenship, and the responsibilities of being-for the other.

Stone notes that, "If Socrates had been acquitted, had he died comfortably of old age, he might now be remembered only as a minor Athenian eccentric, a favorite butt of the comic poets" (3). But Waterfield's research on the actual charges against Socrates contextualizes his crimes, and suggests that his state-sanctioned death might have been inevitable. Either way, in death, Socrates was elevated to iconic status by Plato. What Socrates was released from by his death was not (or, not only) the confines of the body, but the confines of his responsibility towards the other. This notion of *being-for* the other comes into focus in the following chapters.

## Chapter Four

### **“If I had a choice, I’d prefer not to die, thank you very much”: Dignified Death**

Peter Richardson’s 2011 documentary, *How to Die in Oregon*, opens with grainy footage from a home video camera. A woman sits at a kitchen table and pours liquid from a measuring cup into a glass filled with a white powder. She pours a little water, stirs the mixture, pours and stirs as the metal spoon taps rhythmically against the glass. The glass is rested atop a copy of the *Oregon Historical Quarterly*, and voices can be heard in the background. A plate of food is near the glass, and the camera then zooms out to reveal an average American kitchen. The camera then moves into the adjoining living room. The back wall is made up entirely of large windows and look down into lush green, and the room is filled with natural light. Seated on a rumpled bed in front of these windows is a tall man with glasses. His name is Roger Sagner, and he appears to be in his 60s. We see him on the bed, surrounded by family members and by a representative from the advocacy group Compassion and Choices, Sue Dessayer Porter. The cameraperson has walked in mid-conversation. Everyone’s eyes are on Sue. She explains to all there, “He drinks the medication, and that will put him in a coma within a matter of minutes. After that--“ Roger cuts her short. “We wait for me to die,” he says. “We can never predict how long that’ll take” Sue adds softly (00:01:15).

A voice off-screen says, “Now Roger, I talked to the other woman in there and said that you could have some juice or something in there...” (00:01:40). People begin talking over one another, trying to discern which beverage Roger might want. In a warm baritone, Roger shouts over them, “Bring me the goddamn glass!” Sue, a small woman with short brown hair, holds one of her hands up in front of Roger. “Roger, now wait, I

want to make sure before you take it: I'm going to ask you these two questions, and I am serious. You have the right to change your mind" (00:01:54). "My mind's not changing," Roger says. Sue proceeds, leaning down and looking Roger in the face. She asks, "And what will this medication do?" (00:01:58) Roger's response is, "It will kill me and make me happy" (00:02:03). Sue then tells him that he can have the medication, and that they ask that he consume it in 60-90 seconds, but that he not gulp it. "It tastes pretty bad, but you have here a soft drink to chase it down with. Do you have any final words you'd like to say to your family?" Sue asks. He says, "I thank you all for being here." Many family members speak up, uttering "We love you, Roger," as all of their eyes remain on Roger, who is still seated on the makeshift bed. Roger then continues: "I am thankful for the wisdom of the voters of the state of Oregon for allowing me the honor of doing myself in at my own volition to solve my own problems. So thank you all" (00:02:45-00:2:59). When he is finished with his final words, Roger reaches out for the glass containing the medications, and drinks it in 11 seconds. Roger Sagner was the 343<sup>rd</sup> person to die in Oregon under the state's Death with Dignity Act (DWDA). As he lies dying, he begins to sing a slow rendition of "Old Black Joe," and stops only to thank the team who prepared the medicine. "Tell the next person, it tastes woody, but it is not rejectable. It was easy, folks" (00:04:05).

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This chapter offers in-depth analysis of the Death with Dignity Act's appearance on film in Richardson's *How to Die in Oregon*. Whereas the previous chapter grappled with the unknowns surrounding the death of Socrates, *How to Die in Oregon* depicts deaths with haunting accuracy. As a text, the film provides a window into an often vague

life experience: it does not attempt to gloss over the experience, but instead roots it in reality and, in capturing it on film, keeps those who die within the film trapped in the narrative presented by Richardson. The film incorporates the everyday lives of terminally ill Americans as they undergo treatments to increase their lifespans, interact with medical professionals, and attempt to live as normally as possible while being fully aware of their limited time left to live. The film also takes great pains to include loved ones as partners in the telling of the terminally ill patients' stories. In the cases of a few of the individuals featured in the film, the filmmaker is present at the time of death. While the deaths might not be featured on camera, the preparation of the death-inducing chemicals is. In most of the cases, at least audio of the death is made available and played during the film. *How to Die in Oregon* as a documentary falls under the umbrella category of objectifying documentary. An objectifying documentary is a text that has two main goals: "to deconstruct the conventions of the realist style and reveal the artifice behind its supposed immediacy and claim to provide 'evidence' of what happened" and "to tell a story for a rational, 'objectified' point of view" (Capdevila 67). Therefore, the film takes on the appearance of "an epistemological tool informed by scientific rationality" (67). As this chapter discusses, while viewing the film, it seems that the authorial intention is less to persuade or advocate than to present undeniable (visual) proof of what end-of-life really looks. Even more so, in selecting the specific patients that his film follows, Richardson builds a relationship between patient and viewer; using this relationship as a conduit, the film also delivers information about what end-of-life feels like.

Together with the records from the Oregon State Department of Public Health, *How to Die in Oregon* illuminates a not often considered method of dying. As this

chapter will show, the contemporary Western biomedicalized experience of dying is not a passive one. Patients no longer linger while waiting to succumb to their illnesses because so many of the causes of death that impacted Americans in generations past have been negated, or at the very least drastically slowed, by modern medicine. While this is a tremendous feat, it contradicts the widespread cultural belief in medicine's ability to prevent death. Because while it may stave it off, modern medicine cannot eliminate death from our lives. Instead, in the cases of the terminally ill individuals discussed in this chapter, modern medicine has allowed diseased bodies to become immune to death but unconditionally vulnerable to suffering. *How to Die in Oregon* is the most realistic textual representation on death available today. In the film, the suffering denied by much of Western society is made visible, as are the struggles that terminally ill patients go through in subjecting themselves and their families to treatment options—and the often misplaced hope accompanying medical intervention, in some cases—that might not succeed. Together, *How to Die in Oregon* and the documentation from the Oregon State Department of Health offer a more complete understanding of end-of-life in America today. But in becoming an audience to the dying individuals in the film, Richardson requires that his viewers play host to the dying. By making his viewers part of the hospitality inherent within the Death with Dignity Act, Richardson forces viewers to grapple with the conditions of the host-guest dynamic is arguably one of its most unnerving manifestations: a host voluntarily assisting a guest with their end-of-life. This particular manifestation is a form of hospitality that has removed many of the conditions that kept violence at bay. *How to Die in Oregon* invites the violence in and calls it a friend; by watching, the viewing audience becomes complicit in the violence, too.



## **Death in Technicolor**

Roger Sagner was the 343<sup>rd</sup> individual to end their life by taking advantage of a law that Oregon passed in the mid-1990s. In 1994, Oregon passed the Death with Dignity Act (DWDA), a law allowing “terminally-ill Oregonians to end their lives through the voluntary self-administration of lethal medications, expressly prescribed by a physician for that purpose” (Oregon.gov Public Health). The minutiae of the DWDA can be found in Oregon Revised Statute (ORS) Chapter 127.897 s.6.01. The “Form of Request” is officially titled, “REQUEST FOR MEDICATION TO END MY LIFE IN A HUMANE AND DIGNIFIED MANNER” (127.897.S.6.01). In the ORS and on the Form of Request, it is made clear that two physicians must agree that the individual requesting the medication is terminally ill, has 6 months or less to live, and is of sound mind at the time of making the request. At the time of the request, patients must have two witnesses who are not related to the patient or their medical care sign a declaration of the patient’s medical state, residency status, and presence of mind and body at the time of the prescription. On the forms, patients are encouraged (but not required) to inform their family about their decision, and are given space to initial next to one of three options: “I have informed my family of my decision and taken their opinions into consideration”; “I have decided not to inform my family of my decision”; “I have no family to inform of my decision” (ORS 127). No less than 48 hours and no longer than 15 days can pass between the request and the writing of the prescription (ORS 127). Physicians who sign off on these forms and prescribe the medications that they legalize will not be held criminally responsible for their actions (ORS 127.890); “No person shall be subject to civil or criminal liability or professional disciplinary action for participating in good faith

compliance to ORS 127.800 to 127.897. This includes being present when a qualified individual takes the prescribed medication” (127.885.1). The medications consist of an oral dosage of a barbiturate (pentobarbital or secobarbital), and “beginning in 2015, a phenobarbital/chloral hydrate/morphine sulfate/ethanol mix has also been used” (DeathwithDignity.org). A large percentage of the individuals taking advantage of the Death with Dignity Act are enrolled in hospice (Miller et.al. 26), a place where “social work is mandated. Although [it] is not specifically mentioned in the law, social workers are a crucial part of the interdisciplinary teams that serve the dying” (26).

Since it was enacted in 1997, 1,545 terminally ill Oregonians have received prescriptions for the medications. 991 of them have ingested the medications with the purpose of ending their life (“Oregon Death with Dignity Act: 2015 Data Summary”). This means that roughly 64% of patients utilize the prescribed medications in order to end their lives, while 36% had the medications in their possession but chose not to consume them (DWDA Report). The 2016 Oregon Death with Dignity Act Data Summary report reveals that a vast majority of the patients—over 70%—had some form of terminal cancer, and 78% of patients were age 65 or older at the time of their deaths. The median age at the time of death was 73. Data collected by the Oregon Department of Health reveals some significant lifestyle similarities among those citizens who chose to take advantage of the Death with Dignity Act. According to the most recent yearly report, issued in February 2016, the three most pressing end-of-life concerns for those individuals who go through with getting the medications are: decreasing ability to participate in activities that make life enjoyable (96.2%), loss of autonomy (92.4%), and loss of dignity (75.4%). Nearly half of the individuals have a baccalaureate or advanced

degree. Many live in metropolitan areas. The most recent study brought to light that over 90% are white—a static trend since 1997. Historically, about a quarter of individuals are widowed and, at the time of their procurement of the medications, more than 90% of individuals were enrolled in hospice care (“Oregon Death with Dignity Act: 2015 Summary”). Eight years into the DWDA, data revealed that “younger people, those divorced or never married, and those with baccalaureate degrees or higher were more likely to use DWDA,” and “Ninety-seven percent of those who have used the law were White, two percent were recorded as Asian, and one person was Native American” (Miller 29). Through taking this action, there is a certain argument made by the dying individual who seeks out DWDA. This is an active relinquishing of control through a method of control. By taking this measure, the dying individual signals that they are exiting the hospitable agreement, the encounter and obligation to the Other, that gives them identity.

While it passed in 1994, the Death with Dignity Act was only officially enacted in 1997, which was around the time when Dr. Jack Kevorkian was heralded as “Dr. Death,” for his assistance in helping approximately 130 terminally ill individuals in the Midwest to die (Murchison). Paul R. McHugh, M.D., was Director of the Johns Hopkins School of Medicine Department of Psychiatry and Behavioral Sciences during Kevorkian’s assistance to his patients, and when his essay “The Kevorkian Epidemic,” was published by *American Scholar* in 1997. In it, he writes, “Although his acts are illegal by statute and common law in Michigan, no one stops him. Many citizens, including members of three juries, believe he means well, perhaps thinking: who knows? Just maybe, we ourselves shall need his services some day” (15). McHugh goes on to diagnose the

“madness” of all parties involved in the Kevorkian epidemic; Kevorkian, in his medical opinion, is “‘certifiable’ in that his passions render him...’dangerous to others” (15). Those soliciting Kevorkian’s services, McHugh claims, are “mad by definition in that they are suicidally depressed and demoralized” (15). Kevorkian’s actions were polarizing, but they reinvigorated the discussion of healthcare reform during the 1990s—even if it was only because of the infamy that his actions gained. The problems within Kevorkian’s methods were glaring: Kevorkian did not follow proper procedures, and in some cases it was found that those he had assisted were not terminally ill—at least five were not ill at all (Murchison). In contrast, end-of-life advocates in Oregon State were able to more persuasively position Death with Dignity legislation because of the media frenzy over Kevorkian’s lax handling of end-of-life. Simply put, whether directly or indirectly, Kevorkian’s actions instructed Oregon on how to utilize the medical profession in the most hands-off way necessary. Rather than enlisting doctors to build Thanatrons (from the Greek, “death machine”), and Mercitrons (from the Greek, “mercy machine”), for patients, medical professionals needed to guarantee that they would not be retaliated against for their involvement in helping patients end their lives. If they were going to take a risk to help suffering, terminally ill patients, they were not going to end up like Kevorkian for doing it.

### **The Fine Print**

For medical professionals, death has become increasingly vague in the face of technological advancements tasked with keeping human bodies alive. Machines can facilitate organ function in the event of failure or impairment, but they can also prolong life after a person no longer has brain function or the ability to perform the signs of life

on their own. Life support was once a stop-gap to provide more time in which patients could recover control of their bodies and doctors could have more time to help them heal. Now, it is so widely depended upon at end-of-life that many hospital deaths are referred to as “pulling the plug.” If technology has increased the rate of deaths that occur in hospitals, it has also blurred the lines between life and death. Robert Sade, M.D., writes, “Everyone knows what ‘brain dead’ means: a person whose brain no longer works is brain dead,” but that, “The term is used so frequently and in so many different contexts that we should not be surprised that two thirds of people incorrectly believe that someone who is brain dead is not legally dead, and more than half believe that a comatose patient is brain dead” (Sade 146). Brain death is just one of the possible classifications of a patient within the hospital’s framework, and even that classification is fluid. Sade points out that, “some argue that not all the functions of the brain need to be lost for a patient to be dead, only those that are critical in maintaining the integration of the body functions” and that, “loss of these critical functions will inevitably lead over hours or day to cardiac arrest, even with continuing intensive life-support” (146). Still, there are those medical cases where brain death does not really mean death, where “the bodies of some patients who meet all the criteria for brain death can survive for many years with all their bodily functions intact except for consciousness and brain stem reflexes” (146). In situations where a patient is dependent upon life-support for the sustainment of life, Sade posits that “a generally accepted ethical norm is that withdrawal of life support does not cause the patient’s death, rather, withdrawing life support allows the patient to die—*it is the disease that causes the patient’s death, not the physician*” (147, emphasis my own). In “Euthanasia: is it really a bad idea?” Arshad Taqi, M.D., writes an entire section on “The

dilemma of defining death.” He writes that, “Introduction of artificial ventilation and circulatory arrest have redefined the concept of death, which was synonymous with cessation of breathing or circulation; as a matter of fact they were not mutually exclusive, cessation of one would naturally lead to the end of the other” (227). Technology in the hospital, has “enabled patients to live without the ability to breathe,” including brain dead patients, and made “moment of death” a very difficult thing to determine (227). It was “easier to define when people dropped dead due to cardiorespiratory failure; now we understand death as a process rather than a moment” (227). In addition to the problems in defining disease, death itself evades definition. Another problematic area for medical professionals occurs when trying to discern how active a physician must be in providing adequate care to a dying patient. What arises is a gray area in responsibility: is providing drugs to a patient to help them die more quickly different from removing a ventilation machine—and if so, how different? Doctors do not lightly answer questions like these; for patients who have never discussed their desires with family members, the responsibility of making the most hospitable decision is tremendous.

Other issues of terminology arise when we consider who the agent of the death is; Sade is careful to put the blame on the disease. This distinction is intended to shift responsibility away from the physicians who are complying with the wishes of the patient or patient’s family, or are following the care plan that they deem most ethically sound in that particular patient’s case. Ascertaining the agent of death is crucial, and is one of the most important aspects of determining cause of death. The homepage of the Death with Dignity Organization defines some alternatives to ‘natural’ deaths, or deaths that do not occur in hospitals or due to the removal of machinery. For individuals who wish to die

another way, namely, the terminally ill, there are some heavily loaded terminologies to parse through. Physician-assisted suicide (PAS), or assisted-suicide, is “an inaccurate, inappropriate, and biased phrase which opponents often use to scare people about Death with Dignity laws. Because the person is in the process of dying and seeking the option to hasten an already and inevitable death, the request...isn’t equated with suicide” (DeathwithDignity.org). They stress that “the patient’s primary objective is not to end an otherwise open-ended span of life” because something else is killing them. The American Public Health Association concurs, stating that, “assisted suicide is inappropriate when discussing the choice of a mentally competent, terminally ill patient to seek medications that he or she could consume to bring about a peaceful and dignified death” (APHA.org). Suicide does not work as a label, either, since it is intentional and voluntary but is a “permanent solution to a temporary problem” and as such, “ends a life that would otherwise continue” (DeathwithDignity.org). Euthanasia “refers to the act of deliberately causing the death of another person who may be suffering from an incurable disease or condition, commonly performed with a lethal injection” (DeathwithDignity.org). ORS 127 states that, “Nothing in the [Oregon Death with Dignity Act] shall be construed to authorize a physician or any other person to end a patient’s life by lethal injection, mercy killing, or active euthanasia” (ORS 127). In order to fully understand the reasons why some Americans choose, like Roger Sagner, to take advantage of a little-known legal end-of-life alternative, the variations in how stakeholders define these alternatives are key. Death with Dignity does not neatly fit under the umbrella of PAS or assisted suicide, suicide, or euthanasia because by the time individuals come to seek out and take advantage of Death with Dignity, all other active options have been exhausted.

## Modeling Choice

Instead of passively awaiting death, individuals taking advantage of Oregon's Death with Dignity Act are shown to be actively trying to prepare themselves in the event of a worst-case scenario. *How to Die in Oregon* focuses on a number of individuals who are terminally ill and are considering using the Death with Dignity Act to obtain the prescription for the life-ending medications. Per Oregon regulations, volunteers from the Compassion and Choices Organizations counsel the individuals hoping to take advantage of the law. After Sagner's home video, the next segment of the film follows the counseling activities of, Sue Dessayer Porter, one of the group's most active volunteers and the woman who counseled Roger Sagner prior to his death. Richardson follows her to a number of appointments where she visits with people considering the DWDA as an end-of-life option and those who have already taken the steps to procure the medications. En route to one appointment, Porter shares:

When I am going to visit someone, there is always some anxiety. I think that anxiety is productive, and I would never want to become laissez-faire about this whole process. And what I think about is, are they going to understand exactly what it is they're pursuing and what the process is? And also, what is always foremost on my mind is that they know they're in charge and that they're the boss" (00:07:34-00:08:31).

This invocation of anxiety is important; in discussions of death, there is typically some anxiety over saying the wrong thing. For those guests who seek out the special kind of relationship offered by the DWDA, there is anxiety concerning their end-of-life. There is also anxiety experienced by those attempting to be benevolent, kind hosts. The line between helping someone die in their own way and advocating for a specific method of dying is a thin one. In each interaction, Porter opens herself up to the other—the other who could take her offer of assistance as a threat of violence.



Hospitality governs much of the discourse surrounding the Death with Dignity Act in *How to Die in Oregon*. During one of the visits shown, an elderly woman shares with Dessayer Porter that she does not want to end her life, but that her life *has* ended. Now, DWDA will help her to wants to “exit life” (00:08:45-00:08:55). Another shares that she wants the medication “for control” (00:09:18), a sentiment that Dessayer Porter says is common amongst those she counsels. Peter Scott, a 69-year-old man who has just received his diagnosis, hopes to use DWDA when his ALS prevents him from being able to walk and he becomes too much of a burden for his wife, Gail (00:09:30-00:10:34). Gail admits that “this is the way he has thought for a long time,” and shares that she will support her husband. Gordon Greene, 86, tells Dessayer Porter that his interest in DWDA stems from watching both of his parents die horrible, drawn-out deaths. He says, “You can only handle about so much garbage,” and then it is time to find a way out (00:13:13). He refers to the DWDA as offering him a death that is quick and painless and does not burden his family. “It’s the decent thing to do,” he tells Sue and his daughter, Donna. He then adds, with a smile, “For once in my life, I’ll be decent” (00:15:00). Dessayer Porter stresses that Compassion and Choices is not selling an option or promoting a single alternative; instead, she says, they are advocating for choice. In all of these interactions, what is clear is that the individual wishes to control the terms of their exit from the hospitable relationship. Disease—not life—holds them captive. What also becomes apparent is that quality of life is completely relative and individualistic. One person’s livable circumstances are another person’s hell. In offering patients the option to choose their end-of-life, the Death with Dignity Act is first asking them to seriously consider the conditions under which they would continue to be a guest.

In critiques of the film, Cody Curtis, a 54-year-old woman with terminal cancer of the liver is described as the “beating heart” of *How to Die in Oregon*. Curtis, an active, outdoorsy woman who worked as an administrator at MIT and then at the Bio-Informatics Center in Portland, Oregon, had a terrible stomachache after receiving—and consuming—four boxes of chocolate for her birthday in 2007 (Curtis). But something told her that the stomachache was not caused by her birthday celebration, and the next week she visited her doctor. When the scans came back, her doctor “burst into tears,” and sent her to surgical oncologist Katherine Morris. Morris found that Curtis’ pain was caused by an aggressive cancer of the liver “roughly the size of a grapefruit,” and because of the positioning of it, they only had “one shot” to surgically remove it (00:17:00-00:17:45). There were no other viable treatment options. The first surgery went well, but during recovery, Cody Curtis ended up in the ICU for 50 days—in a coma for many of them. Cody’s husband Stan tells Richardson in an interview: “the night before her second procedure, she was supposed to be taking pain medication pills. She was throwing up and couldn’t keep the pills down. So the pain medication was wearing off, so she said, I don’t ever want another night like that” (00:18:01-00:18:34). It took 6 months before Cody was able to walk, use the restroom, and feed herself without the help of others. She was completely dependent upon her hosts/family, and could not keep up her end of the hospitable arrangement. She was barely alive. During a checkup a few months after being released from her lengthy hospital stay, the cancer was back—and it was more aggressive. Her medical team gave her a prognosis of 6 months or less. At that point, Cody told Dr. Morris that she wanted to have the Death with Dignity Act “in reserve” in the event that her health digressed significantly. In the film, Morris tells Richardson: “It

was strange to think about it in the intellectual realm, where this is a law that supports my values...I'm actually going to take a pen and write a prescription for something that will end someone's life" (00:19:17-00:20:35). Morris' sister, a breast cancer survivor, convinced her to help Cody. "You're her doctor. You have to help her," she stated (00:20:45). And so Morris wrote the prescription. "Cody taught me that 'first, do no harm,' is going to be different for every patient. Harm would have meant taking away the control and saying, no, you've got to do this the way your body decides as opposed to the way you as a person decide" (00:21:20-00:21:41).

Cody shares that one of the worst parts about being as ill as she is—and both Richardson and Cody's healthcare team make clear throughout the film that she is *incredibly* ill—is the limbo of having a diagnosis and prognosis, but not really knowing what is going to happen. As the film progresses, Cody ebbs and flows. She has no idea what the next day will bring, or when things will get bad enough that she can no longer care for herself. However, "With Death with Dignity, you do know, though, and have some control over what's going to happen. You can offer that to your family" (00:24:01-00:24:18). As Curtis grows sicker, her husband and daughter are supportive of her decision to end her life on her terms, but her son has a more difficult time rationalizing her need for Death with Dignity. He shares his concerns with his mother, who discusses them with him at length. In the end, though, she convinces him that her pain is severely inhibiting her experience of her own life, and that she does not need to suffer for anyone—not even him. "Of course I would if I thought there were a real chance, but there's not" (00:26:10-00:26:17).

### **Struggling-For**

The second chapter of this project dealt with the death of Socrates and the *being-towards-death* that he experienced during the final weeks of his life, which I argue influenced his activities during his imprisonment and immediately prior to his execution. While waiting for uncontrollable events to come to pass, Socrates was caught between life and death, freedom and confinement. For the contemporary individuals featured within *How to Die in Oregon*, and the innumerable number of terminally ill Americans who might want to die differently, the period of *living dying* can be excruciating. While caught there, individuals are repeatedly forced to come into contact with the limitations of themselves. These confrontations call one's entire being into question. Michael Hyde calls these moments the "call of the conscience," moments when our existence as Beings, a thing we take for granted, is shaken. In pursuit of reparation of our fractured sense of self, we call out to that self through our conscience. In "hearing the call," we are, in a sense awakened to begin the process of putting ourselves back together. We become "concerned with the truth of our temporal existence and with the decisive challenge that comes with it—trying to determine how to live out this truth" (25). For those who hear it, "the call of the conscience brings us face-to-face with the fact that we are creatures whose desire for the 'good life' requires us to assume the personal and ethical responsibility of affirming our freedom through resolute choice" (25). The call of the conscience, then, forces individuals to fully consider their actions and their motivations. Acting responsibly requires a kind of rhetorical openness to the Other, a desire to listen and connect with those who are outside of one's self but also familiar. This plays out in real, practical ways when it comes to the issue of end-of-life. One of the most moving aspects of *How to Die in Oregon* is the irrefutable way that the individuals featured in the

film live for one another. For many of them, there is a struggling-for the other that is a simple, resolute choice. But there are also limitations to that generosity, or a closure to the rhetorical openness. And this space, betwixt the philosophical and the practical, is where things become incredibly interesting. It is within this space that hospitality comes into play, since the overarching intention of the individuals in *How to Die in Oregon* to find the “at-home” of the self again.

Every individual featured within *How to Die in Oregon* wishes to die within their own home, surrounded by the familiar. At its most basic level, the familiarity of home offers up safety. Within the known boundaries of the home over which one is sovereign, the individual can relax and allow itself to be exposed; there is no real threat inside the home. The threats are within the patron of the house, the person in charge, and they can be allowed to breathe within the safety of the home. In Plato’s *Phaedo*, Socrates long-held conception of the soul as a combination of reason and desire is given a new configuration. For the Socrates of the *Phaedo*, the body is the site of desire and the soul is pure reason. Given that Socrates’ death is imminent in the *Phaedo*, it is interesting and understandable that he would suddenly consider his body a distracting kind of cage. This concept, which seems purely theoretical within the pages of *Phaedo*, comes to life onscreen within *How to Die in Oregon*. Bodies are cages that hold in a sovereign *Dasein*, a presence of human existence that has literal boundaries. For the individuals who are, in a way, trapped within those bodies as disease ravages their interiority, dying in a familiar space offers the possibility for some control over circumstances. By controlling that sovereign space, the dying individual can possibly regain some control over some of the conditions of dying.

In *Being and Time*, Heidegger writes that, “Dasein is mine to be in one way or another...That entity which in its Being has this very Being as an issue, comports itself towards its Being as its ownmost possibility...*authenticity* and *inauthenticity* are both grounded in the fact that any Dasein whatsoever is characterized by mineness” (*Being and Time*). Where Heidegger believes that nothing is as personal and internalized as the *Dasein*’s own death, Levinas sees death as a kind of communion. Heidegger’s suggestion is that individuals live for themselves and only know others because that knowledge helps constitute their separate individuality. But in watching the interactions of the *living dying* with the living in *How to Die in Oregon*, the Heideggerian approach rings false. The dying do not live for themselves at the end, or at any other time; they live for one another and adhere to a response-ability that is called forth from them. As Levinas writes in *Totality and Infinity*:

To be I is, over and beyond any individuation that can be derived from a system of references, to have identity as one’s content. The I is not a being that always remains the same, but is the being whose existing consists in identifying the itself, in recovering its identity throughout all that happens to it. It is the primal identity, the primordial work of identification” (36).

This calling forth creates a community. For Levinas, identity is fluid *because* it is constructed by all interactions with all others. Levinas considered the confrontation between the fluid self and the others who call it into being to be an ethical one. Blackwell is careful to point out that when Levinas diverged from the work of Heidegger, it was because Heidegger viewed death as an opportunity for the Dasein to prove itself, but “Levinas does not view death, however, in this way. Rather than see it as the ultimate test of virility and authenticity, as the proof of mineness, his ethical reaction is to view it as the other’s death, in which we recognize the limits of the possible in suffering”

(Blackwell 4). In the Preface to *Totality and Infinity*, Levinas writes, “The visage of being that shows itself in war,” (and this chapter argues, in all high-conflict confrontations with the other), “is fixed in the concept of totality, which dominates Western philosophy. Individuals are reduced to being bearers of forces that command them unbeknownst to them” (*Totality and Infinity* 21). While these confrontations open the individual up to the other, “War does not manifest exteriority and the other as other; it destroys the identity of the same” (21). So the individual, when met with resistance from the other during war or conflict, is not fighting just the other, but also his own Being. This is one piece of Levinas’ larger ethical project. Rather than needing the *Dasein* to die in order for it to legitimate its presence and its separateness from the others, death allows *Dasein/Being* an opportunity for *connection* to the others. In dying, there is a rhetorical opening outwards. That opening creates an opportunity for face-to-face recognition and real understanding of the suffering of the dying. In breaking with Heidegger, Levinas “has thought the farthest” of any philosopher “about human mortality not, as one might imagine, by standing on Heidegger’s shoulders, but rather, more originally, by proposing a radically different but philosophically superior account of the nature and significance of human mortality” (Cohen 23). Levinas “radically and completely” opposes Heidegger’s approach to death; where Heidegger believed that *being-towards-death* was “the self-understanding of being,” Levinas believes death to be “beyond-being and better-than being” (25-26). Levinas focuses on the death of the self least and the death of the other is where he invests his analysis since this is the precise point when “care for the other’s death takes precedence over care for one’s own—all the way to the extreme point of ‘dying for’ the other—that the human subject achieves its true humanity, and hence the

proper height of a morally and socially responsible selfhood” (25-26). This approach emphasizes that the “*Human* consists precisely in opening oneself to the death of the other, in being preoccupied with his or her death...But above all, it is no longer just a question of going toward the other when he is dying, but of answering with one’s presence to the mortality of the living. That is the whole of ethical conduct” (Levinas 164).

The ethical conduct of being present at the death of the other is what viewers offer the subjects of *How to Die in Oregon*. Richardson’s documentary is itself a narrative that traces the decline of its subjects and becomes a living text. As a documentary film, it embodies a kind of “deep-focus realism,” a style of documentary that, “resembles everyday experience in that both share a certain spontaneity and freedom in the scanning of the surrounding area” (Carroll 241, Capdevila 68). Carroll writes that this style, in attempting to present real life as realistically as possible, gives the illusion of freedom in the editing of the film; the audience perceives this control as assimilation of “the succession of images” and calls the freedom “realistic because it is analogous of the kind of choice and freedom we experience when we scan everyday reality for information on how things stand” (68). As Capdevila suggests, “if documentary images satisfy our thirst for reality, it is because they also shape our way of looking at reality” (69). In watching beings individually come-to-terms with their finitude, a shared experience emerges. The terminally ill patients and their families are finding the boundaries of themselves on film, and as viewers, we hold them suspended in their suffering. We are the host who knows what is coming. Despite our freedom in viewing and how real the documentary feels as it objectifies its subjects and subject matter, as audience members, we are complicit in the



violence that holds the terminally ill hostage within their bodies. Documentary films toy with temporality, weaving and unweaving the narrative in a way that seems real (as in, something that we are viewing in the now), but is already past. Instead of being able to connect with the individuals who we hold hostage in our viewing, we are incapable of freeing them or altering the conditions of their stay within our homes.

As we watch *How to Die in Oregon*, we are given insights into the lives of guests who we did not anticipate ever knowing, and who we will never know. At the most basic level, as viewers we are anxious about having to witness someone die; there is something about it that seems voyeuristic, as though we are invading upon the most personal and private of life's experiences—in a sense, we are the uninvited. But on a deeper level, our anxiety arises because as hosts to these guests, we are not sure which actions to take. The reception of *How to Die in Oregon* is evidence of audience reluctance at even this passive participation in end-of-life. Brooks Barnes of the *New York Times* writes that, “Most screenings at the Sundance Film Festival here are mob scenes...none of that hubbub was on display at the Sunday premiere of what is without question one of the most difficult-to-watch movies of the festival, this year or any year” (Barnes 1). HBO produced the documentary, and Sheila Nevins, the president of HBO Documentary Films, shared with Barnes that “she thought people were squeamish. Even half her staff—and this is not a crew unaccustomed to difficult topics—refused to watch the whole film” (Nevins qtd. in Barnes 2). Additionally, “the movie's experienced publicity team said it had never witnessed such universal can't-cope-with-that rejection from members of the media at Sundance, who left some empty seats at the screening.” Some of those who stayed for the entire film openly sobbed. Nevins adds: “Nobody wants to stare death in the face, and

that's the reason nobody wants to see this film...Don't get me wrong—it's very harsh, a very hard watch. But ultimately it's an important film about courage, about dignity, about compassion" (Nevins qtd. in Barnes 2). While we might want to look away and leave death to the dying, *How to Die in Oregon* forces us to look death in the face and to consider the next ethical step. While we cannot play an active role in easing the stay of these guests, can we really deny them our consideration?

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**“What is happening to me?!”**

During Cody Curtis' first cancer diagnosis and treatment, she wound up in the Intensive Care Unit due to complications that arose from the surgery. “I was in a coma for quite a while, and all of a sudden, I opened my eyes really wide and said, ‘What is happening to me?!’” (00:17:30-00:17:59). *What is happening to me* is the question of the *living dying*, the question that the Being asks in order to understand itself again, in an attempt to re-identify itself to itself. It is a difficult question to ask, and for the terminally ill, an even more difficult answer to receive. One of the most dramatic aspects of *How to Die in Oregon* is how invested the audience becomes in the story of the dying individual, Cody Curtis in particular, receiving a different type of message. When Richardson first begins interviewing her on tape, she has just received a second diagnosis of liver cancer, it has metastasized to other organs, and she has been given a prognosis of 6 months to live. But after 6 months, Richardson reacquaints us with Cody. We watch her gardening in her front yard. We hear her excitedly talk about the “golden summer” that she and her family have shared; it is a summer that they did not think she would live to see. She tells Richardson that she is no longer worried about dying all the time, and that if she had it to

do over again, she would not have chosen a date to end her life. Miraculously, she is feeling better. As an onlooker, we exhale a sigh of relief. When she shares in an interview that she thinks about not dying now, and finds herself wondering if she might have “another twenty years” to live, we feel as though we have been let off the hook, because if she is healthy, we are not responsible/response-able for her choices.

But we are responsible, and response-able. Death is “at once resistance and urgency of life, or as Levinas put it, ‘healing and impotence’” (Tangjia 143). Tangjia writes that, “In fact, death takes root in care. For Heidegger, care becomes the way of humans to escape from the fear of approaching death. Although the person who has died is not in the world any longer, he is still alive in the image and memory of others, and he is still the object which others care about” (146). And this care includes the tributes we pay to the dead in our mourning of them, including the funeral rites and the celebration of the life they lived. Accordingly, this ethic of care serves as the foundation for Levinas’ discussion of responsibility. For Levinas, the matter of death was one meant to be dealt with by the living. Meaning is derived from death by the “survivors in the family in which the dead person lived,” by those hosts who were beholden to their guest in life and, now that the guest has left, must go through with moving forward. In Levinasian terms, fear of death is built into our lives from a pre-ontological place. “Our consciousness is usually occupied with Being and the ‘il-y-a’ to the point that we find ourselves unable to accept or take over impending death and nothingness” (147). It is beyond our grasp. When it confronts us and we are forced to consider it more fully, we are forced to ask *what is happening to me?!*

The next time Richardson interviews Cody Curtis, she is talking to Linda Jensen, her Compassion and Choices volunteer. Cody tells Linda she feels “really guilty” about feeling healthy months after outliving her prognosis (01:01:08). She shares with Linda that the guilt arises from her inability to meet the expectations of those around her; there are expectations of how she should behave and what should happen, and in being alive, she is not meeting those expectations. When she learned she only had 6 months to live, Cody made a checklist of the things she wanted to accomplish prior to death. But when we see her an hour into the documentary, she says she has been “dragging her feet” on the last few items on that list because she does not know what she will do when it is finished. There is a fear of the unknown here. For well over six months, Cody has been spending her days waiting for the cancer to kill her, or for the pain to be so great that she turns to the medications she has stowed away in a drawer in her home. Much of her anxiety now stems from not knowing what to do with herself. She is not declining, and she wants to “conform” to the expectations of illness, or, the narrative that prognosis layers onto life. She looks at Linda and says:

And then you said something profound when we talked on the phone. You have to decide what quality of life is. Is it just being able to get up and get dressed and take a walk, or is it not having pain? I’m coming to think it’s not being able to take care of myself and not worrying my family. And I feel like I wanna model—for my children—a kind of grace and acceptance. And I’m really scared of being a coward at the end. (01:02:03-01:02:39).

Linda answers Cody: “Do you think it’s cowardice to not want to suffer?” (01:02:49).

She goes on, telling Cody that the problem in society is the notion that the “truly courageous are the ones who suffer the most” (01:03:06-01:03:21). “There’s no logic, there’s no logic to that,” Linda tells her. Cody considers this and says, “It’s a very human thing to die...I’m just lucky to know how and when I’ll die and to have more control over

that then most people do” (01:03:42). And so Cody goes about her life, free from debilitating symptoms for a few more weeks.

When the decline happens, though, it happens quickly and is excruciating to watch—even more so to endure. Cody has outlived her diagnosis by 10 months and is on high doses of morphine for her pain. Richardson follows her into her darkened kitchen where she opens a deep drawer filled with various prescriptions and vitamin bottles. Her breathing is audible and labored. “It’s hard to sort out...what’s doing what,” she tells him. Her fevers are spiking, she is not responding to antibiotics, she is in pain, and she’s jaundiced (01:13:40-01:14:09). “So yeah...I’m declining the last week and a half” (01:14:28). Because she is suffering but able to care for herself for the most part, Cody is now torn; the decision to end her life is one she is not ready to take lightly, even though she is fully aware of what her decline will look like. She says that there will come a point where the choice is “easy and obvious and I’ll be grateful,” but she is not there yet (01:15:08). In an attempt to buy herself a little more time, Cody has another procedure done in order to remove some obstructions from the tube that allows her liver to function. Because the tube had become blocked, fluid was building up in her abdomen. Cody is conscious but under anesthesia while they replace her tube and begin draining her abdomen of fluid buildup. As liter after liter (four total) is filled with excess fluid from her abdomen, the doctors tell Cody that she should experience profound relief now that they have relieved some of the pressure causing her not only physical discomfort, but rendering her incapable of eating. When she sees the fluid in the jars, a groggy Cody begins cheering on her doctors. “Pat yourselves on the back. Group hug if necessary,” she tells them. She then begins to weep. “I’m so happy. Thank you,” she tells a nurse

(01:20:30). While it cannot save her life, modern medicine has bought her a little more time. Immediately following this procedure, Cody's husband Stan does another interview with Richardson. He shares that this is not about an unwillingness to suffer, or a rejection of the face of suffering. Stan believes that his wife was willing and ready to suffer in order to achieve a graceful death; the nature of her disease is what prohibits this kind of death from happening, not her willpower. And in his support of her decision is a self-proclaimed pride in her, in the family they have created, and a recognition of the her pride in herself. "I don't think that gets talked about often enough," he tells Richardson (01:21:52).

Unfortunately, the procedure only buys her a little more time. Walking becomes more difficult, and so does the ability to tolerate the pain. Food begins to lose its taste, and Cody can barely keep it down, anyway. Cody and Stan visit Dr. Morris, and Cody asks for the decision tree going forward. Cody tells Dr. Morris, "I'd like to know what will it be like if I decide not to treat the fevers, because I just feel like I'd just rather drift away" (01:23:27). The fevers have risen to 104 degrees, which tells Dr. Morris that the bile in Cody's liver is infected, and that the infection is life-threatening. Her options are whittled down to one. She can continue treating the fevers and prolong her current state of suffering, or she can stop treating the fevers and to fall into a coma induced by the infection, at which point she will likely only last a few more days. As the reality sinks in, Richardson keeps the camera focused on Cody while Stan and Dr. Morris try to get themselves to the point of realization that she has already gotten to. Stan voices his support of a third option—more draining of fluids, which would possibly buy Cody more time. "Jill, really, is set on coming home for Christmas on December 23<sup>rd</sup>. So there's a

fair amount of incentive to see if draining helps to get us to there” (01:24:35). Dr. Morris breaks in, “Certainly, I think we could see if the drainage could help get things through to Christmas” (01:24:52). Cody then turns to Stan and says, with tears in her eyes, “Well, I think this is enough. I, I, I can’t do anymore” (01:24:58). And just like that, the decision has been made. The camera zooms out and we see Dr. Morris, Stan, and Cody all coming to the same point of recognition. Before we leave them, Richardson zooms back in on the space between Cody and Stan: their hands are tightly gripped together.

Two weeks after this very difficult conversation, Cody’s liver is failing. A message on the screen tells us that “the build-up of fluid in her abdomen continues, at a much faster rate” (01:25:43), and opens onto a scene of Cody getting her final haircut. Her midsection is extremely bloated due to the collection of fluids. She struggles to get comfortable in the hairdresser’s chair, a struggle that she will be actively trying to hide within the rest of the film. A voiceover during the haircut features Dr. Morris. She tells us: “About three weeks ago, Cody was on a very minimal amount of pain medication. Within the last three weeks, she’s gone to needing the equivalent of 10 mg of IV morphine an hour, which is...a lot. Part of the pain is due to the fact that she has literally, like, 3 two-liter Coke bottles of fluid in her belly. It’s like going from not-pregnant to nine months pregnant in a week, and she said, ‘This is not what I signed up for. I’m suffering now. And, um, so, it’s time’” (01:26:23-01:26:47). Cody tells Richardson that she does not wish to “subject her family” to having to watch her needlessly suffer while she waits to die. While she can “understand that there is a kind of dignity in suffering, there is a certain grace in accepting the inevitable” (01:26:59-01:27:14). Dr. Morris guesses that, given the support of the hospital staff, if Cody were to try to die naturally,

she would need a great deal at the end of life in order to die at home: a hospital bed, round-the-clock nursing staff, and intravenous medications, among other expensive and time-sapping endeavors. It is the week before Thanksgiving, and given these ‘extras,’ Dr. Morris estimates that Cody would still be dead within approximately eight weeks.

Instead, Cody chooses to pass away on Monday, December 7, 2010. Saturday, December 5, 2010, is spent with friends and family. Cody is trying to have a perfect weekend. Her daughter Jill flies in early, and in the two days before her death, Cody teaches her son how to make the family’s favorite cookie bars—a recipe everyone loves but no one but Cody knows how to prepare. Friends visit and she encourages them to ‘shop her closet.’ She gives a few small gifts to others, at which point both she and her friends sob. During all of this, her son cooks in the kitchen and every so often, brings in a pot or a pan for Cody’s approval. She is too sick to stand for very long, and is mostly confined to laying on her back in bed. After everyone leaves, he brings in an emptied pot of melted chocolate for her to have the last lick of the spoon, but she is too sick to eat it.

When Monday comes around, Richardson does not take us into the bedroom where Cody will drink the medications. Instead, the closest we get is a kitchen table where the medications are prepared. He positions us outside of the house, focused on the warm light shining through the curtains in Cody and Stan’s bedroom. We can hear the family singing together. We travel between kitchen table and this outside-looking-in view. Linda, Cody’s volunteer from Compassion and Choices, pours the secanol capsules into a shallow bowl, one by one. The mound of medication nearly fills the bowl by the time she is done. From outside, we hear Dr. Morris arrive. Inside, we see Stan watching as Linda mixes water into the secanol. Once the mixture is ready, we hear Cody telling



her friends and family how much she loves them. Sniffling and crying are heard, then Cody telling everyone that there is “holiday Kleenex in the next room” (01:41:12). Cody tells Stan she loves him. Linda hands the mixture to Cody, and reminds her that it will taste terrible. We hear people shuffling. We hear Cody thank Stan for “a great weekend” (1:43:30). Then, “thank you, momma and daddy for coming” (01:41:20). “And, thanks for singing me out” (01:41:40). And her final words: “This is so easy. I wish people knew how easy this was. Thank you, Dr. Kate...I’m drifting, I’m drifting” (01:44:46). Someone in the room begins to whistle a song, low and slowly, and the film ends.

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*How to Die in Oregon* is a brave documentary, and that is perhaps what makes it difficult to watch. It asks its viewers to become hosts to dying and to give the dying the benefit of their presence. This interaction is an ethical one; in being present and preoccupied with the death of the other, viewers come to understand their finitude. In representing the Death with Dignity Act as an end-of-life option, the film also familiarizes us with things we do not typically see: patients receiving medical treatments, patients suffering from their diseases despite medical treatments, and suffering bodies moving around in society.

In *Totality and Infinity*, Levinas refers to suffering as “the pain lightly called physical” (69). Cohen writes that in describing pain in this “dramatic” way, Levinas is defining suffering that comes “from the enforced passivity of the sufferer. That is to say, pain occurs in a doubling up of pain: there is pain and like a shadow there is also its inescapability, which is part of and increases the painfulness of pain” (28). In this suffering resides the fear of death. For Levinas, “The acuity of suffering lies in the impossibility of fleeing it, of being protected in oneself from oneself; it lies in the being

cut off from every living spring. And it is the impossibility of retreat” (238). In viewing the film, the audience is implicit to the suffering of the film’s subjects. And the suffering is what is most striking within the documentary. For instance, the film makes it plain that Cody Curtis desperately wants to make it to Christmas for her family, the others who have given her life meaning and who will live on long after her. When she admits to her husband and Dr. Morris that she cannot—and will not—go through with more treatments, the agony is visible on her face. When they each tell her that they will support whatever decision she makes, that agony is replaced with relief. Death is a “social event” that connects the dying to those who have come to offer their presence, their community, to the suffering individual. This is why while looking on and observing the suffering of the individuals within Richardson’s film we are caught up in hospitality, Derrida’s Mobius-like in-between of hospitality and hostility. But in viewing this kind of suffering and looking directly at it, viewers have an occasion to consider mortality and morality.

Relief is what is offered by the Death with Dignity Act, not death. This is because the Death with Dignity Act offers users autonomy in medical-decision making and agency in controlling their own deaths. Individuals who seek out, apply for, and obtain the life-ending medications often report “the comfort of having the prescription or the medical in hand” (P. Miller et. al. 27). For those individuals who procure the medications and do not take them, the ability to access an end-of-life option is enough. It provides them with the sense of having made an informed, independent decision, and allows them to utilize that option if and when they are ready. Approximately one-third of the individuals in Oregon who receive the medications do not use them to end their lives. For the roughly two-thirds who do, the stakes are different. Through the Death with Dignity

Act, they are able to consider “the role of suffering and meaning at the end of life,” and act of their own volition. A group of hospice workers in Oregon who counseled these individuals write that, “Now, to know that a capable and competent patient could take a lethal and legal dose of medication to end his or her life on a specified day opened new clinical challenges to social work’s education and knowledge” of end of life (P. Miller et. al. 32). Many times, “open conversation about the choice for Death with Dignity in the context of wishing to hasten death appeared to decrease the patient’s anxiety and distress” (33). For patients ‘stuck’ there, dwelling in the in-between is an unending confrontation with finitude and the body’s deterioration. The terminally ill individuals utilizing the DWDA worry about the effects of their deaths on those around them. Loved ones are held captive by the illness, too, and their brushes with death leave indelible marks. The desire to maintain the connection to the Other is natural and human, so it makes sense that while alive, the loved ones of the dying individual would follow them anywhere. In Cody Curtis’ case, and in the cases of so many others utilizing the Oregon law, death with dignity is an end to the struggling-for the other, and is instead a way of liberating the other from their responsibility.

Dying with dignity under the Oregon Death with Dignity Act is no easy feat. This law has quietly offered Oregon citizens an alternative to extended suffering for the past two decades, and has been successful because it is rooted in best practices. In requesting such an allowance from Western biomedicine, dying individuals must come face-to-face with their limitations and with their lack of personal agency. But Levinas is correct in thinking that these confrontations with mortality have a way of crystallizing one’s views. For the individuals featured in *How to Die in Oregon*, this clarity puts one’s dignity into

focus—not into question. For many of them, dignity has little to do with vanity or personal pride in one’s health. Instead, it has to do with honoring the life one has lived, the family one will leave behind, and the death that is least painful for all involved. Through watching the film, it becomes increasingly obvious that the real tragedy would be in asking these individuals to continue living lives that are so full of suffering. In asking the *living dying* to endure deterioration and physical pain, the living put the possibility of a dignified death at risk. “Because of the waiting periods involved and the requirement of self-administration of the medications, waiting until far into the disease process may make use of the law unattainable” for some individuals (P. Miller et. al. 34).

There are examples of this less easy death. When waiting too long to take advantage of a particular option that is both legal and dignified, other less dignified options begin to emerge. These are last-ditch efforts at gaining control and agency in the face of death. Zoe FitzGerald Carter’s *Imperfect Endings* is one recent and often shockingly honest portrayal of such a descent into fewer and fewer options. The memoir begins when FitzGerald Carter’s mother, Margaret, decides to end her life. She is tired of suffering from Parkinson’s disease and discusses her end-of-life options with her physicians and her three daughters. FitzGerald Carter and her sister Hannah support their mother’s decision, but their sister Katherine is not of the same mind. Katherine chooses not to participate—in the discussion, carrying out their mother’s plan, or being there for their mother’s death. This is a common, and very human, response in the face of death. But Margaret perseveres despite criticism from family and some friends. A native of California, she has no access to the legal options. When she realizes her lack of legal options, she devises a plan to skirt the law. She attempts to get enough morphine

stockpiled so that she can take it all at once when she is ready. But she can never get enough, and the time just never seems right.

Instead, she starts seeking out other options, carefully choosing which friends to tell about her decision. There is no consensus. She tells Zoe, “I called Mitzy up on the Cape. She told me she did not approve of what I was doing. She said I was being selfish” (196). But in the same breath, she adds, “It’s okay. I don’t expect everyone to understand” (196). Despite efforts to persuade someone to give her medications to end her life, she is unsuccessful. And as she cannot gain access to legal life-ending medications, what transpires is a months long seesaw between trying to weigh the value of one’s potential future against present suffering. Inevitably, Margaret tries to overdose on morphine, but doesn’t die because she did not take enough. Ultimately, she realizes that starvation is her best option—a process that takes nearly two weeks before she finally succumbs to it. That duration of time takes a tremendous toll on her daughters and their families. FitzGerald Carter writes, “*People die the way they live*. Big public gestures had never been my mother’s style and now that I think about it, I see that the dramatic deathbed scene with the morphine wasn’t her at all. Slipping away unnoticed in the midst of an ordinary afternoon was all her” (246). Through her grief, she realizes that, “After all these months of discussion, the false starts and failed attempts, my proud, determined mother had died on her terms, grace and dignity intact” (246).

Biggs writes that “human dignity...is a nebulous concept amenable to a range of interpretations”; for patients who seek dignity at the end-of-life, “living may amount to little more than survival” (11). Being kept alive at the risk of one’s dignity prolongs dying but takes a significant toll on the *living dying* individual. The nebulous nature of

these circumstances raises questions concerning the definition of life and death, but also highlights the problematic and nebulous issue of quality of life. It seems that especially for the terminally ill, being kept alive is not a primary concern. It becomes a secondary or even tertiary concern in the face of suffering and illness. Of greater concern are the needs and experiences of family members during the dying, the way that things are left once the dying person's life ends, and the circumstances the living are left to deal with when they are left behind. The living-for Others that is cultivated during entire lives is made strange by death. For those taking advantage of the Death with Dignity Act, dignity is one last kindness to offer to family and friends who have stood by during illness, and to one's self. In Oregon, this dignity is built into citizens' rights—they have the right to avail themselves of the law if their suffering is too great, and the State protects the rights of those who survive the terminally ill individual. But for those who do not reside in Oregon, the struggle to attain a dignified death is complicated by abstract geographical boundaries. We are all going to die; in Western biomedicine, the way that we die has become controlled by complicated by politics, geography, and our own unwillingness to have serious conversations about end-of-life. For some individuals, this lack of hospitality is unacceptable. Instead of accepting their circumstances and limitations, they work from inside the system that prevents them from fully exercising their rights and, from that position, effect change. While the dying cannot control their decline, the documentary provides them with the opportunity to control of their own narratives and to discuss the death of the other. In doing so, they make a kind of timeless sacrifice in the vein of what Levinas considered the most extreme sense of mortality and “perhaps the ultimate sense of morality, living for and caring for others,” that being “dying for the

other” (Cohen 30, Levinas 216). In dying for the other, we make it our purpose “to not let the other die alone,” and “worry over death of the other comes before care for self. The humanness of dying for the other would be the very meaning of love in its responsibility for one’s fellowman and, perhaps, the primordial inflection of the affective as such” (216). By putting the comfort of the suffering other ahead of one’s own, the individual who is other-oriented can perform the most ethical kind of morality, where “concern for the death of the other is realized, and that ‘dying for him,’ ‘dying his death,’ takes priority over ‘authentic’ death” (217). In a way, this ‘dying for’ inverts the hospitable relationship. It gives up one’s own sovereignty for the betterment of society at large; it is a tremendous sacrifice. But theoretically, in orienting one’s self towards a more caring kind of morality, Levinas enables individuals to recognize their responsibility at members of society, a responsibility that is “incumbent on beings as beings, specifically on mortal and suffering human beings,” who, although they be “separate from one another,” must “rise to a higher, nobler, responsibility, to care for one another...the other who as a mortal being suffers and should not face death alone...who imposes the moral demand to be saved from the violence of death” (Cohen 38). In viewing *How to Die in Oregon*, the documentary’s audience is asked to participate in this kind of responsibility and to confront the death of the other. Inherent within this confrontation lurks the question over what happens when this sense of responsibility—in being present for the dying of the other—falls apart.

## Chapter Five

### Looking Death in the Face: Brittany Maynard's Search for Hospitality in Dying

*“To undergo an experience with something means that this something befalls us, strikes us, comes over us, overwhelms us and completely transforms us. When we talk of ‘undergoing’ an experience, we mean specifically that the experience is not of our own making; to undergo here means that we endure it, suffer it, receive it as it strikes us and submit to it.”*

Emmanuel Levinas, *Otherwise Than Being*

*“Bodies/Can’t you see what everybody wants from you?/  
If you could want that, too/Then you’d be happy.”*  
St. Vincent, “Cruel”

Something happened in America in late 2014 that made it difficult for American society to continue ignoring death's existence: a young American woman found out that she had terminal cancer and, rather than opting for experimental and doomed treatments, chose to access an end-of-life option available only to a select group of Americans living in states with legal end-of-life options. In the months between diagnosis and death, 29-year-old Brittany Maynard became the spokesperson for medical aid in dying and the American public took unprecedented interest in her decision. Bioethicist Arthur Caplan attempted to rationalize the public's fascination with Maynard, speculating that, “because she's young, vivacious, attractive, a newlywed, has a dog, and is a very different kind of person from the average middle-aged or older person who has to confront issues about terminal illness, she changes the optics of the debate” over how terminally ill Americans should die (“Why Brittany Maynard Changes the Right-to-Die Debate”). Fresh optics proved vital in Maynard's positioning as an advocate for aid in dying; she did not fit the image of terminal illness that Western society is familiar with and so quickly shies away from, and for the first time, people were listening to a discussion of death.



In this chapter, Maynard's position as a suffering subject is examined. Levinas considered death to be a pre-ontological issue of ethics. In Levinas' line of thinking, and in *Totality and Infinity* in particular, morality is necessarily an obsession with the death of the other and a preoccupation with caring-for that other in their time of greatest need. While the prognosis that Maynard received is unfortunately all-too-common, her handling of her prognosis set her apart and invited the public to encounter death in a more comfortable way. Rather than denying death, the American public was invited to witness the overcoming of suffering—to take part in an ethical interaction and, through their interest in the Maynard's end-of-life, to reexamine their personal feelings about death. But in asking the public to allow her to end her suffering, Maynard also asked them to engage in a kind of hospitality without protective conditions: Maynard's death engaged in its own kind of hospitality, too. In sharing her suffering with others and allowing them to come to terms with their mortality, she required something in return: that more terminally ill Americans were allowed to legally opt out of their suffering.

### *No Vacancies*

In "Hostipitality," Derrida discusses the spaces in which hospitality dwells. He writes that, "There is almost an axiom of self-limitation or self-contradiction in the law of hospitality. As a reaffirmation of mastery and being oneself in one's own home, from the outset hospitality limits itself at its very beginning, it remains forever on the threshold of itself" (14). He continues unspooling this idea, claiming that in order to understand hospitality, one must "take up the figure of the door, for there to be hospitality, there must be a door" (14). Hospitality is defined by the freedoms of both the guest and the host; both are responsible to one another, and their shared home must have doors and

windows in order to assure them of their mutually beneficial confinement within the relationship. But Derrida is clear that there is a difference: “In visitation there is no door. Anyone can come at any time and can come in without needing a key for the door. There are no customs checks with a visitation. But there are customs and police checks with an invitation” (14). The difference, then, is one of entering willingly into a hospitable relationship and finding oneself already part of a relationship without being complicit. This distinction, much like the hospitality/hostility struggle described by Derrida in this article and throughout his work, is fluid. It depends, as always, on context and circumstances that are often beyond the individual’s control.

As a citizen of the United States, Brittany Maynard was afforded certain rights. However, since the right to die is left up to individual states, Maynard was beholden to her home state’s laws on the matter. As a resident of California, she was first and foremost a guest of that state. But her visitation became complicated when she made an unexpected request of her host. When Brittany Maynard received her terminal diagnosis, she initially “considered passing away in hospice care at my San Francisco Bay-area home,” but chose not to because “even with palliative medication, I could develop potentially morphine-resistant pain and suffer personality changes and verbal, cognitive, and motor loss of virtually any kind” (Maynard). Her condition became particularly frightening when her physicians cautioned her that because she was “young and healthy,” she was “likely to physically hang on for a long time even though cancer was eating [her] mind” (Maynard). Like so many of terminally ill citizens in Oregon discussed in chapter 3, Brittany Maynard wanted to approach end-of-life with an option in ‘reserve’. As her seizures grew more severe and the realization of her imminent, violent death became

undeniable, Maynard prepared herself to do what was necessary to access the type of death that felt dignified to her. It would have to be one that enabled her to maintain autonomy and quality of life. Additionally, it would need to provide her with a sense of control in the midst of her unexpected prognosis, decline in health, and overwhelming anxiety at the thought of suffering. When she considered her options, the laws of hospitality had a great deal to do with how she weighed the possibilities. Hospitality plays a significant role in how one is treated in any situation where they come into contact with others. Derrida defines hospitality in terms of an almost pre-ontological sense of responsibility towards the stranger, the other, writing, “hospitality is certainly, necessarily, a right, a duty, and obligation, the *greeting* of the foreign other as a friend” (OH 4). But for Maynard, the friendly treatment she longed for was unavailable from her host state. Frustrated by her lack of access, Maynard very publicly made a decision to disentangle herself from what had been a lifelong hospitality arrangement. In doing so, she raised questions about patient autonomy and patients’ rights at end-of-life, successfully reinvigorating discussions of human rights in the process.

Understanding and alleviating patient frustration is most critical for the terminally ill, since once diagnosed, they must quickly come to terms with how out of their control their death is; death is instead *controlled*—by state and federal governments, Western biomedicine, and the inescapable tension of hospital-patient co-dependence, for starters. As Jodi Halpern writes, “The term *autonomy* refers to both a psychological capacity to make decisions that reflect one’s own goals and an ethical ideal of self-determination” (Halpern 101). Modern medicine has long attempted to provide its patients with autonomy, and within the medical context, the “term is used...to describe an evolving set

of patients' rights, extending from rights to determine what happens to one's own body, to rights to informed consent and refusal of treatment, to rights to participate more fully in medical decision-making" (101). But illness manipulates autonomy, since it is a situation that the individual may not know how to navigate and needs professional help with. However, studies of how healthcare professionals communicate responsibility/response-ability to patients with chronic and terminal illness, Thille and Russell found that most care fell short of providing patients with a care plan that considered individual needs and concerns. Instead, in attempting to convince patients to take responsibility for their health, most medical professionals were actually urging them to think of their illnesses as "measurable" and scientific, rather than sets of occurrences that could provide insights; "patients' lived experience" was deemed unreliable and unscientific precisely because it could not be measured (1348). In these instances, the patriarchal tradition of medicine seems to be at work. Doctors "give responsibility," meaning that they provide "medically defined measures of disease activity" and expect patients to keep themselves within those measurements. "However, when patients 'took control' in ways that were not allowed by doctors, their actions were presented in negative terms, as problem behavior," and they were seen as non-compliant (1349). The guests had overstepped their boundaries and not acted within the conditions set forth by the hosts. In instances where illness is serious and threatens to end patient life, patient agency and autonomy are compromised in significant ways. The ill become dependent upon the healthcare system and its agents but in trying to perform responsible self-care, they are often perceived as failing to take responsibility. In this dependent relationship, where healthcare professionals play host to the suffering guests, "success was constructed

as more complex than what was observable or measurable, and in some cases, only known by the patient” and imperceptible to the healthcare professional (1348). In reality, for healthcare to break out of the doctor-centered model and become more collaborative, it must strive for more “mutually negotiated goal[s],” since these are the only types of goals that, because of their dependence on “patient involvement in planning care, in part because patient concerns were constructed as (often) incongruent with disease-specific, physician-identified priorities,” can yield satisfying results for both patient/guests and their conditionally generous caregivers/hosts (1349). But this kind of care requires that the long-held standards of care be revised in order to provide more hospitable care. Not all participating parties are convinced that, by decreasing the conditions placed upon contemporary medical patients, overall healthcare will improve. By removing conditions, Western biomedicine loses its footing: if it is not the all-powerful sovereign, then it is more susceptible to violence.

The desire for patient-centered care is not new, but Maynard’s requests reached new audiences. For the terminally ill, “how we die has been an issue mainly fought out by the elderly, some patient advocacy groups for the severely ill, disability organizations, pro-life groups, religious organizations and healthcare providers. Most of the combatants are middle aged or older. Few are especially photogenic. They have been sparring with one another for a very long time” (“Why Brittany Maynard Changes the Right-to-Die Debate”, Caplan). When Brittany Maynard went public with her health issues, the results were dramatic. She welcomed relationships based in hospitality, and in longing for death, invited it in on her own terms and in agreement with the laws of opening herself up to all others. “Hospitality can only take place beyond hospitality, in deciding to let it come,

overcoming the hospitality that paralyzes itself on the threshold of what it is...In this sense, hospitality is always to come, but a 'to come' that does not and will never present itself as such, in the present <and a future that does not have a horizon, a futurity—a future without horizon>” (“Hostipitality”, 14).

### **Agency Transformed**

Maynard began suffering from severe, debilitating headaches around New Year's Day of 2014. A few months later, she had undergone a partial craniotomy and a partial resection of her temporal lobe to remove a Grade 2 astrocytoma. However, scans 70-days post-op revealed that the cancer was actually an aggressive Grade 4 astrocytoma, known as a glioblastoma, and Maynard was told she had 6 months or less to live. What followed was a familial scramble to enter into drug trials, to find answers, and Maynard, her new husband, her mother, and her stepfather quickly realized that no matter which treatment options she went forward with, Maynard would not buy herself enough time to really make a change. She was going to die, and her death was going to be a painful one. When she sought out medicalized solutions to aid her in dying—after all, she was a 29-year-old Californian who had always previously been able to depend upon modern medicine—she was told that her home state would offer her no help. They would give her drugs to numb the pain and drugs to help prevent her increasingly frequent seizures, but they would not provide her with the kind of ultimate hospitality that she wanted from them. When considering her options, Maynard came to the conclusion that she wanted to obtain the medications available through the Death with Dignity Act. However, Maynard's medical options were inhibited by location: because she lived in California and not Oregon, she could not receive the medical care that she desired. Due to their lack of legislation on

end-of-life, her home state of California could not provide her with anything other than hospice and palliative care. In order to gain control over her inevitable death, Maynard and her family uprooted their lives and relocated to the state of Oregon in order to establish residency and begin the process of utilizing the DWDA.

When asked about end-of-life, a significant number of Americans—roughly 70%-claim that they want to die in their own homes. Individual motivations for wanting to die at home may vary slightly, but a desire to die while surrounded by familiarity is natural. Biggs writes that, “In modern Western culture death has traditionally been a private affair occurring behind closed doors and with minimal observation. Yet in Britain today,” as in America, “approximately seventy percent of all deaths occur under the bright lights of hospital where the natural processes of dying are often transformed into a medical event and subordinated to technology” (Biggs 9). This is a trend among Americans as well. Despite the desires of the patient, dying within the hospital is what is offered. In lieu of hospital deaths, the closest thing to choice that patients receive is hospice, which is heavily controlled and actually quite difficult to be admitted to. But, as one social worker who specializes in hospice in the state of Oregon stated,

“Do you think there is comfort for physicians because they refer the patient to hospice? I think that [a referral to hospice] is probably happening more often than we know it, because I see it from people, too, that the physician wasn’t interested in discussing” other options with them, “and they didn’t quite know where else to go...Nobody had given them any direction so it [the desire to utilize Death with Dignity] was out there with their physician, but it was now too late.” (Norton and Miller 254)

Physicians who are reticent to discuss end-of-life with terminally ill patients are not necessarily ignoring their obligations as health professionals; instead, it seems more

accurate that this group of physicians is not comfortable offering that particular option because of the expectations inherent within the hospital's brand of hospitality.

But in not offering a full array of end-of-life options, doctors are exercising an unethical control over their patients' deaths. In practical terms, hospitality only functions because of its intimate relationship to spaces that serve as markers, since "the law of hospitality as the law of the household...the law of a place (house, hotel, hospital, hospice, family, city, nation, language, etc.), the law of identity" (4). Hospitals provide patients with a well-defined and limited agency; they can complain of discomfort, ask for assistance, undergo treatments, and even move freely through the institution. But their physicians-hosts trust them to behave as patient-guests, and people die everyday within the hospitable relationship structured and controlled by the Western biomedical model. In *Life's Dominion*, Ronald Dworkin writes of another daily occurrence: "Every day, rational people all over the world plead to be allowed to die. Sometimes they plead for others to kill them. Some of them are dying already...some of them want to die because they are unwilling to live in the only way left open to them" (Dworkin 179). These individuals are actually pleading for a Levinasian kind of ethics, as if to say, *if you won't die for me, won't you at least watch me while I die?* But doctors have an ethical obligation, even in the face of patient suffering, to keep patients alive. The notion that guests want to end their lives while under the protection of their hosts calls the relationship between patients and doctors into question, especially since the purpose of Western biomedicine is to prolong patients' lives. Davis writes that "once an uninvited 'guest' (a parasite, then) makes its way in, announces itself inside, 'every element of hospitality gets disrupted...all the dichotomies presumed by hospitality 'in the classic



sense' collapse: private/public, interior/exterior, self/other, host/guest" (Davis 131).

When these dichotomies collapse, an individual's sense of being is changed; they may become protective of the life that they live, but as research has shown, it's more likely that that will collapse, too. And in Brittany Maynard's case, when these collapsed constructs were made public through her activism, they ruptured the blissful ignorance that many Americans enjoyed concerning end-of-life issues. In reality, what doctors are fighting against is disease and illness that is inextricably linked to the body. The fact that the *Dasein*, the person's humanity and soul, reside within that body is not medicine's primary concern. In a sense, individual need gets in the way of the entire mission of curative medicine.

California's ability to meet Brittany Maynard's needs as a guest was impossible—and in their rejection of her request, they rejected her as they would an unwelcome foreign visitor. For her entire life, Maynard seems to have existed in a pleasurable hospitable relationship with her home state. However, in her moment of greatest need, the state did not meet its ethical obligation: it refused to be present for her at her time of death. In "Hostipitality," Derrida suggests that, "One can turn the person who arrives away on condition that *this does not lead to his death*...If the stranger behaves himself, however, we cannot turn him away. But this also means there is conditionality. What are the limits? What is the content of these conditions?" (16, emphasis my own). In turning Maynard down/away, California forced Maynard into a peculiar hospitable relationship with the state of Oregon. In demanding that this need be not only recognized, but *met*, Maynard altered the conditions of her stay as a guest. She was able to extricate herself from one hospitality and change the terms that all future

guests will have to abide by. Maynard's individualized approach to death was motivated by her own needs as a dying person, but it was also done in order to be there for others—to meet the ethical need in *dying-for* others.

The conflicts here are real. There are ethical, moral, and legal issues within the issue of an individual's right to not only the death of their choosing, but to die at all. In the case of terminally ill Americans residing in one of the 45 American states without death with dignity legislation, the limits are physical and geographical. These limits violated Maynard's sense of her rights; in requesting something of her host, a host that had supported her and allowed her ample freedom for a lifetime, the host had rejected her conditions. In order to achieve an end to her suffering, Maynard had to break the laws of hospitality. In this breaking is violence, which Levinas stated, "is necessarily a trauma, a shattering of the self and world, not an appropriation but an experience of depropriation and alteration from which there is no return" (74). While these lessons altered Maynard irrevocably, California was not entirely to blame. By providing her with that type of medical care, Maynard's physicians would have been breaking state law and opening the host/hospital up to substantial legal risk. They would have essentially murdered a guest who was under their care and violated their position within the structure of hospitality. In playing God in order to help Maynard gain control, they would have engaged in a kind of hospitality that was without conditions.

When Brittany Maynard relocated to Oregon from California in order to gain access to DWDA, she went public with her decision, and was featured in *People* magazine and PeopleMagazine.com the morning of October 6, 2014. Within the first 24 hours of the 6-minute video being posted, over 400,000 people viewed it—the most

attention of any publication on that website to date (Compassion & Choices). The headline, “Terminally Ill 29-Year-Old Woman: Why I’m Choosing to Die on My Own Terms,” was widely shared in the United States and abroad, and garnered a great deal of media attention for the cause of aid in dying. In addition to her contributions to popular magazines, Maynard was interviewed on most of the major news outlets and attempted to explain her decision-making process: “I’ve had the medication for weeks. I am not suicidal. If I were, I would have consumed that medication long ago. I do not want to die. But I am dying. And I want to die on my own terms” (Shoichet). After the initial announcement of her decision, Maynard refocused her message: she did not just want to die on her terms. She wanted others to have the option for medicalized aid in dying, too. And she did not want them to have to uproot their lives in order to gain that access.

Like Cody Curtis in *How to Die in Oregon*, illness and the treatment of it had left her physically altered. In the interviews leading up to her death, Maynard looked different from her pre-diagnosis photos: she shared with interviewers that “Medication had drastically changed her appearance” (CBS). While Maynard had chosen not to undergo complete brain radiation because of the physical side effects, stating, “The hair on my scalp would have been singed off. My scalp would be left covered with first-degree burns. My quality of life, as I knew it, would be gone” (Maynard), the decision to stave off disease through approved pharmaceutical treatment ravaged her body in undignified ways. Her internal pain and suffering had been made visible to all others who came into contact with her; she was now distinguishably foreign and strange. But her appearance was not the only thing at risk of being altered by her disease. In an interview in October of 2014, Maynard stated: “I still feel good enough, and I still have enough joy,

and I still laugh and smile with my friends enough that it doesn't seem like the right time, right now. But it will come, because I feel myself getting sicker..." (Shoichet, Compassion & Choices). She went on to discuss the foreign sensation of being in a body that was not healing from illness, but growing weaker by the day. She said she no longer felt like herself and that she did not enjoy being photographed, filmed, or looking in the mirror—not because of "self-loathing," but due to a complete lack of recognition (Compassion & Choices). In expanding upon her experience, Maynard shared her personal worst-case medical scenario:

The worst thing that could happen to me is that I wait too long because I'm trying to seize each day, but then I somehow have my autonomy taken away from me...most recently my most terrifying set of seizures, about a week or so ago, I had two in a day—which is unusual. I remember looking at my husband's face and thinking: I know this is my husband, but I can't say his name. (Compassion & Choices)

The prospect of being confined within a space against her will—held hostage by a dying body and a terminal illness that would rob her of her identity—was unfathomable for Brittany Maynard. Going through with that kind of death would have necessitated an unconditional welcoming of a particularly gruesome death. And her fear resonated with a death-averse American public who, for reasons unknown, were open to hearing her message.

Maynard made her intentions to end her life on November 1, 2014 (just 5 days after her husband's birthday), public as early as October 14. As the 'due date' drew near, public interest in Maynard reached its zenith. Medical ethicists weighed in on the debate on various news outlets, the Catholic Church condemned Maynard's activism, and various terminally ill Americans who did not support the Death with Dignity Act reached out to Maynard in attempts to change her mind. However, on November 1, 2014,

Maynard followed through with her plan and consumed the lethal prescriptions intended to end her life. Her family reported that she passed away “peacefully” (“Why Brittany Maynard’s Death Was an Ethical Choice”, Caplan). Maynard’s death was popular news in the days that followed—as was the Catholic Church’s official condemnation of her actions (McKenna). Upon receiving news of Maynard’s death, Monsignor Ignacio Carrasco de Paula, the Vatican’s top ethicist, told Italian news agency ANSA, “We don’t judge people, but the gesture in itself is to be condemned” (de Paula qtd. in McKenna). He continued, calling her death an “assisted suicide,” and claiming that such an act was an “absurdity,” stating: “Killing yourself is not a good thing; it’s a bad thing because it says no to life and to all that means in relation to our duty in the world and to those close to us” (de Paula qtd. in McKenna). de Paula’s official statement illuminates the power of Maynard’s decision. Some noted that her approach to the end-of-life movement contained “no new arguments,” but also that her critics were not bringing anything “novel” to the debate (Caplan, “Bioethicist: Why Brittany Maynard Changes the Right-to-Die Debate”). de Paula’s concerns reflect that Maynard’s death had more of an impact than even she anticipated. Condemned or not, change had already begun.

Scott Graham and others have begun to trace patterns of change within Western biomedicine, and have found evidence of paradigmatic shifts being possible within what is a very rigid structure. When they do occur, these shifts begin on the level of changing opinions. If there is scientific proof to support the change, then changes are likely to begin. For example, Graham notes that contemporary theories about agency “provide rhetorical scholarship with the following” parameters for measuring substantial change:

1. Agency is the process of instantiating change in the status quo.
2. Change arises from series of rhetorical events over time.

3. Although the overall agentive program resists authoritative forces, the constitutive rhetorical events frequently rely on those same authoritative forces.
4. A change becomes the status quo when the (new) authoritative structures operate to maintain the change. (Graham 379-80)

When taken together, these pieces make collective efforts to effect change possible. (This pattern of change is not just theoretical, but practical, such as when a group of engineers found their work to be the “result of a conjunction of opportunities” (Winsor 427)).

Change is really the result of “taking advantage of a series of events, over time” (Graham 381). Changes do not necessarily need large buy-in to begin; they can also be implemented by the actions of individuals within a small sphere. For Maynard, diagnosis presented access to medical facilities and treatments; terminal illness provided the *kairos*, and Maynard seized the moment. Maynard’s decision to advocate on her own behalf was one facet of changing the status quo; the more substantial impetus behind change was Maynard’s advocacy and petitions to other American states. Maynard’s message was widely disbursed by the Compassion & Choices, a nonprofit organization advocating for patients’ rights at the end of life—primarily medical aid in dying. A former *Sunday Times* reporter, Derek Humphry, started the Compassion & Choices Organization, originally the Hemlock Society, in 1980. Humphry had relocated to the US in the 1970s, and became an advocate for aid-in-dying when he assisted his terminally ill wife in committing suicide after a terminal breast cancer diagnosis in 1975 (Gabriel). In 2003, Hemlock Society was swallowed up by two advocacy groups—End-of-Life Choices out of Denver, Colorado, and Compassion in Dying, out of Portland, Oregon. What emerged was Compassion & Choices, an advocacy group with a somewhat sordid history and an investment in issues that had long been debated but not worked through. Medical aid in dying, also called

physician-assisted suicide, is their primary cause. They had worked under the radar for nearly two decades before Brittany Maynard approached them and became their new spokesperson.

### **Towards Ethical Hospitality**

Just three days before her death, Maynard shared a phone call with California Governor Jerry Brown while she was in Oregon (McGreevy). While the specific details of their conversation are impossible to know, Maynard's family and Brown's office both stated that Maynard was "appreciative of the opportunity to give Governor Brown a firsthand account of why she was in favor of similar legislation in California" (Diaz qtd. in McGreevy). The Governor's official statement was careful to point out that Brown "did not make any commitment on legislation" during or immediately after the phone call. His discussion with Maynard can be read as an act of hospitality, though, since he opened himself up to the conversation and allowed her to exercise a great deal of autonomy in pleading her case. It seems implausible that Maynard's situation did not influence Brown's feelings on the topic. While alive, Maynard was articulate, calm, and warm. There is no reason to think that she was any different while conversing with the governor of her beloved home state—a place she had always lived and had hoped to spend a full life. While speaking, the two must have both realized that Maynard would never see California again, and that she died feeling as though she had been turned away in her moment of greatest need.

For individuals seeking end-of-life alternatives, the inflexibility of the Western biomedical model reads as hostile. Derrida writes: "Anyone who encroaches on my 'at home,' on my ipseity, on my power of hospitality, on my sovereignty as host, I start to

regard as an undesirable foreigner, and virtually as an enemy. This other becomes a hostile subject, and I risk becoming their hostage” (*Of Hospitality*, Derrida 54-55). This encroachment holds both guests and hosts hostage in their responsibilities to one another. Despite the interdependence between host and guest, when individuals wish to take advantage of an alternative that is not legal within their home state, decision-making power is severely imbalanced. The right to hospitality has been denied, and the guest is not protected within the host’s domain. Skewed power structures prevent progress, and leave it up to frustrated individuals to either disregard the systems that leave them bereft of autonomy and/or find ways to work within systems to regain that agency. Maynard’s efforts circumnavigated the system preventing her from dying the way she wanted to; her experience also drastically increased public attention to the issue of aid in dying during the height of the controversy she created. After her death, small changes started happening, and these changes provide possible avenues for substantial reform in end-of-life care.

Eleven months after Maynard’s death, Governor Brown signed California’s ABx2 15, a controversial bill known as the End of Life Option Act. The bill, modeled on Oregon’s 1997 Death with Dignity Act, makes it possible for “an adult who meets certain qualifications, and who has been determined by his or her attending physician to be suffering from a terminal disease, as defined, to make a request for a drug prescribed pursuant to these provisions for the purpose of ending his or her life” (Assembly Bill No. 15). When Governor Brown signed the bill, his office issued a statement, which was called “unusually personal in nature” by news sources (Megerian). In it, Brown stresses the care and consideration taken in his decision to support the bill. Brown writes that he



had discussed the bill with “doctors, religious leaders and those who champion disability rights,” considered the “theological and religious perspectives,” and even “discussed this matter with a Catholic bishop, two of [his] own doctors and former [seminary school] classmates who take varied, contradictory and nuanced positions” (Brown). Brown, who had studied to become a priest, was 77 years old when he signed the bill. By 2015, he had endured three separate cancer experiences—basal cell carcinoma that was removed from his ear in 2008, a cancerous growth removed from his nose in 2011, and treatment for early stage prostate cancer that began in 2012 (York). Brown closes the official document by stating:

“In the end, I was left to reflect on what I would want in the face of my own death. I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn’t deny that right to others.” (Brown)

Since California is the most populous state in the US, with approximately 38.8 million residents, when Brown signed the bill into law, he essentially provided 1 in 10 Americans with access to an additional end-of-life option (“Population”; Coombs qtd. in McGreevy). Brown’s discussion of his motivations calls to mind Levinas’ thinking on death—that the individual comes to terms with death by making the death of the other his business. In considering the needs of the other and using his position to stress the obligation that states/hosts have towards their residents/guests, Brown, too, became an advocate for increased end-of-life rights.

California’s bill was made into law less than a year after Brittany’s death. All parties involved credited Brittany Maynard with the legislative change. Barbara Lee Coombs, the president of the Compassion and Choices organization describes the

relationship between Maynard and her organization as “a perfect match.” She shares that, “Brittany was a captivating personality,” and upon meeting her, people generally felt as though they were “meeting a friend” (“Brittany Maynard’s Legacy” 00:00:13-00:00:23).

When Brittany came forward with her desire to end her life through the Death with Dignity Act, there were only a handful of bills like Oregon’s in other states. In the weeks and months directly after Maynard’s death, that number ballooned. Lee Coombs shares:

“Brittany’s emergence made lawmakers all over the country want to introduce bills to solve the problems that she illustrated. To give you an example: in 2014, there were aid in dying bills in 4 states. Immediately after Brittany’s emergence, lawmakers in 25 jurisdictions, plus the District of Columbia, introduced bills.” (00:04:42-00:05:01)

It was a feat that the Compassion and Choices organization had been striving for in its various manifestations since 1991; by broadening the message’s audience, Brittany Maynard accomplished it in under a year. What Maynard realized was that death impacts everyone and denying it does not ease one’s confrontation with death when it finally does occur. Rather than rejecting it, an ethical approach is to give it one’s full consideration.

By refusing to openly acknowledge death, Western culture actually gives death tremendous power over human life. Individuals are held hostage by their fear and anxiety over what death will be like. As evidenced by Maynard’s efforts and her impact on end-of-life legislation around the United States, this does not have to be the case. Maynard’s success in spreading her message is wrapped up in who she was as a person and how she lived her life. First of all, she was educated and independent. When her prescription for the life-ending medications was filled in May 2014, she was in Alaska on a trip with friends and her husband had to pick up the life-ending medicines for her (“Brittany Maynard’s Legacy”). In life, Maynard was invested in a wide range of experiences and

had already learned to cultivate and nurture interpersonal relationships. She referred to the friends and family who shared her final moments with her as the “ring of love,” and the majority of her final months were spent traveling and making memories with these individuals. Maynard knew not only her own value, but the value of her one short life.

In addition to this is a more obvious but less inspiring reason: Maynard’s youth and relative attractiveness. For a majority of Americans, the advantages available to citizens of Oregon State were only well-known to individuals in that part of the country. The “Brittany Maynard’s Legacy” video on the Compassion and Choices website features Dr. Robert Olvera, a California physician whose daughter died just months shy of the California End of Life Option Act being signed into law. Dr. Olvera’s daughter had already died, but he shares that even as a physician, he had no idea that the End of Life Option Act was legal in other states. When his daughter asked him to provide her with “sleeping pills so that she could sleep forever,” he had to deny her request; it was illegal. (00:05:03). After her death, he joined Maynard’s family in their efforts to make end-of-life alternatives available to all Americans. But Maynard opened the door. Perhaps the sense that those who came into contact with Brittany Maynard has something to do with this; if, as Coombs Lee suggests, Maynard was consciously making an effort to be more open to the other—to all others—then her interactions allowed for a greater sense of connection. Due to her illness, these otherwise friendly interactions presented those who came into contact with Maynard with responsibility: they had now come face-to-face with the *living dying*. Would they deny this obviously suffering individual the right to a dignified death? Would they demand that the other who had welcomed them continue to exist in pain?

Much has been made of what I will refer to as Maynard's potential for suffering. Other terminally ill Americans wrote letters and made public videos begging Maynard to reconsider ending her life with the Death with Dignity Act. In ending her life through legal alternatives, they felt that Maynard was playing god and taking on too much power over her choices. But as Levinas makes clear, suffering is an individualized experience. We might witness its manifestation on the face and body of the other, but the other suffers alone. Others cannot suffer in one's stead; they might sacrifice themselves for the other's well-being, but in terms of terminal illness, *dying-for* does not eliminate disease. For Maynard, the looming fear was this: that she would be locked in, incapable of actively participating in her own dignified death. She would be held hostage without the possibility of being released, except through death. And this possibility was made especially unsavory when the strength of her very young body was taken into consideration. After weighing the possible outcomes, Maynard decided there was no acceptable amount or method of suffering once that suffering crossed a boundary and became a complete loss of agency.

In considering Maynard's approach to end-of-life, research done on hospice workers dealing with Oregon's Death with Dignity Act and from the perspective of compliant healthcare professionals is useful. In "Conversations at End of Life: The Challenge to Support Patients who Consider Death with Dignity in Oregon," Pamela J. Miller et. al. find that the basic factors influencing the varied responses to end-of-life assistance fall into four categories: "mental health, education, and choice; team concerns; family issues; values, ethics, and restricted conversations" (P. Miller 31). Miller's research, as well as Tolle's, points out that "long before Oregon's DWDA legislation,

terminally ill patients have considered hastening their death and pondered under what circumstances they might feel compelled to do so” (31). Some patients end their lives while under hospice care, a practice that is legal in Oregon under the DWDA, but happens less often than patients dying in their own homes. Of this practice, Miller writes “Because of the unique challenges of dealing with” DWDA, “it is vital that staff work closely together to address their concerns and feelings and to be thorough and thoughtful in their assessments, so that no one person on the team feels a greater burden or responsibility” (35). Care plans are an integral part of hospice care, and Death with Dignity forces caregivers to expand their care offerings and their approaches to end-of-life discussions with patients. In hospice and other compassionate end-of-life settings outside of the home, the responsibility to fulfill the patients’ end-of-life choice becomes shared by all caregivers.

Healthcare professionals employed by Oregon’s religiously affiliated hospitals experienced the most significant issues in dealing with the Death with Dignity Act (P. Miller 38-39). In Oregon, one hospital with doctors on polar opposite sides of the Death with Dignity debate experienced a “bitter and visible debate” that led to the hospital and doctors’ frequent inclusion in local media and attempts by both sides to utilize their positions to “recruit others to their points of view” (38). This seismic debate occurred at just one hospital; the divisions at others are strong but less destructive. For social workers who come into hospitals in order to work with patients and healthcare professionals on DWDA issues, conflicts between doctors and nurses over their views on DWDA created occasions where “what felt like conflicting mandates of the health system to not discuss DWDA that in turn collided with the profession’s code of ethics which aims for patient

self-determination and access to information, resources, and services” (39). Ultimately, patient self-determination is what is at stake in the Death with Dignity Act. Brittany Maynard’s activism on behalf of herself and other terminally ill Americans casts this end-of-life option in a new light and potentially shifts the very difficult positions that healthcare professionals and caregivers find themselves in when all entities are not focused on the patient’s personal desires for end-of-life. By choosing not to participate in treatments and trials that would extend her life only by weeks, Maynard took the burden of decision-making into her own hands. Her doctors only had to write a prescription and allow her to exercise her legal options.

Brittany Maynard’s experiences pushed for the type of paradigmatic shift described by Graham. Agency was gained through increased awareness about end-of-life and the experiences of terminally ill Americans in particular. Then, that agency was channeled into informative, rhetorical events. Maynard created a set of rhetorical artifacts that were convincing and persuasive. Once her advocacy had a narrative, Maynard was careful to situate her cause in terms of the other available options. Likewise, while she resisted the condemnation of religious and political entities, she utilized existing power structures in order to obtain the medications and the type of death that she desired. She did not break any state laws; in fact, she relocated so as to obey the laws of her home state. But in doing so, she expressed her dissatisfaction as this lack of hospitality. While her personality might have endeared her to those who came in contact with her, the factor that seems to have made significant change possible was Maynard’s reasonable approach. She was able to articulate her desire for hospitality and used what was left of her life to channel her agency into advocacy. Maynard had to re-learn her position and to spend her

final months fighting for her right to die, but through her death, she eased the struggle of Others, and provided them with an access to a different kind of hospitality. She opened up and altered state legislature, illuminated the dark corners of the end-of-life conversation, and irrevocably changed the way that death is approached by the *living dying* dependent upon Western biomedicine.

## Chapter Six

### A Second Opinion: Medical “Games” Offer an Alternative Perspective

*“Confronted with the end of the world, we simply tune out or enter the realm of fantasy.”*  
–George J. Annas, *Worst Case Bioethics*

*I could remember how my father used to say that the reason for living was to get ready to stay dead for a long time.*  
--Addie Bundren, William Faulker’s *As I Lay Dying*

Thus far, this project has analyzed the positions of various stakeholders in the end-of-life debate. As shown throughout the preceding chapters, concerns over the procurement of a ‘good death’ can be traced as far back as ancient Athens. Essentially, for as long as groups of individuals have lived together in communities, they have been concerned with how the ill are treated. And once they have passed, virtually all cultures have some investment in the funerary rights of their dead. But as technological intervention has increased human lifespans, a great deal of cultural pride has been taken in Western biomedicine’s ability to prolong life and avoid considerations of death altogether. To this point, the perspectives discussed in this project have given attention to perspectives that are supportive of increased end-of-life options, and death with dignity in particular. Whether from a medical, legislative, or personal perspective, reasons for increasing the dignity of the *living dying* abound. This chapter, however, is rooted in a different kind of idea about end-of-life situations: what if living is the anxiety-inducing state of being than an individual hopes to avoid? What if dying is a more enticing alternative to the individual’s life?

In thinking through these questions, this chapter analyzes a particular interaction between doctors and patients depicted in an episode of the American television show *House, M.D.* There are a number of reasons for selecting this particular a television show



as a site for analysis. *House, M.D.* ran for 8 seasons from 2004-2012 on the Fox network. It was extremely popular and most Americans are familiar with it. Additionally, the show is a fictionalized medical drama that emphasizes the power of the medical gaze and diagnostic medicine. Jonathan Gottschall claims that although “Plato tried to ban fiction from his ideal republic,” fiction does change human psychology in ways that are becoming measurable. The “research consistently shows that fiction does mold us,” and “fiction seems to be more effective at changing beliefs than nonfiction, which is designed to persuade through argument and evidence” (1). The research shows that in reading texts that are “nonfiction, we read with our shields up. We are critical and skeptical. But when we are absorbed in a story, we drop our intellectual guard. We are moved emotionally, and this makes us rubbery and easy to shape” (2). The research on the psychology of fiction-consumption suggests that overwhelmingly, “fiction shapes us for the better, not for the worse” (2). This is a reasonable suggestion, given the manner in which fiction allows its viewers/readers to engage with perspectives that are different from their own; in consuming fiction, viewers also consume—and must digest—swaths of contemporary culture that cut “across religious and political creeds,” and deepen our sense of morality (3).

In “Games,” the fictitious hospital’s head of oncology, Dr. James Wilson, is confronted with a strange situation: he gets to tell a patient whom he had previously diagnosed with inoperable cancer and given 3 months to live that there was a mistake in the scans and tests and that he is actually not dying of cancer. Using this encounter as a starting place, this Chapter argues that end-of-life confrontations have the power to dramatically shape the individual’s desire to live. In terms of hospitality, being given an

‘expiration date’ via a medical prognosis is akin to being given an eviction notice. Essentially, the guest is being told that their stay is limited, and they are given time in which to prepare for departure. Much of this situation echoes Socrates’ final weeks of life. While confined to a prison cell and awaiting trial, Socrates knew that death was imminent and kept himself busy making amends for past wrongs, creating music, and speaking with friends about the meaning and value of his life’s work. These are reflective practices, meant to give us a sense of accomplishment: if we have completed all of the things we were supposed to, then we can depart on good terms. In Western culture, these efforts now fall into the category of “bucket list” items. If these “bucket list” items give purpose to the final months or days of a dying person’s life, it is necessary to question what gave that life meaning prior to a diagnosis and prognosis. However, when presented with death, not all individuals are driven to create, to harness their anxiety and *being-towards-death* and produce something meaningful. These are the individuals of interest within this chapter.

By and large, hospitals are believed to “dehumanize patients by silencing their voices and stripping them of their biographies” (Kaufman 95). In submitting to a healthcare professional’s prescribed conditions, the patient acts as a pliable and compliant guest. But this submission does not maintain the suffering individual’s identity. Not only do patients and families experience deindividuation within these constructs, but “less visible and more insidious are the ways in which hospital structure itself organizes and routinizes dying and life-prolongation,” beginning with the notion that “individuals can only act within systems of classification that already exist,” to the alarming insight that “neither those who work in the hospital nor those who travel through it control the

classifying systems or define the frameworks through which medical problems and their solutions are understood” (95-96). Western biomedicine’s endeavors are deeply contingent upon the spaces they inhabit and the individuals who enter those spaces. While, “Forty years ago, hospitals were looked at as trusted friends,” in recent years, “there has been a relative decline in positive feeling about hospitals, because of all the attention to medical errors, the fear of hospital-acquired infections and the commercialization of medicine” (Salvador qtd. in Pear). Additionally, doctors struggle with the ethical imperatives of their jobs, as suggested by a recent study of 7,000 doctors. Over half of the survey respondents felt that end-of-life issues placed them in the most difficult ethical dilemmas and presented “the biggest [ethical] quandaries,” with over a third of the respondents answering with “it depends” to questions about providing life-sustaining therapy when it was futile, and ceasing or providing life-sustaining therapy due to familial demands (Kane 2). Additionally, 45.8% believed that physician-assisted suicide should be allowed “in some cases,” and 13.5% answered “it depends” to the same question, meaning that almost two-thirds of the respondents felt that their role as a medical professional could include either making decisions about ending a patient’s life or providing patients with access to life-ending materials (2). Within contemporary medicine, both patients and doctors are held hostage by the laws of hospitality, and by their prescribed roles within the imbalanced doctor-patient relationship. In Western biomedicine, struggles like these play out in very real doctor-patient interactions daily. For the sake of this chapter, though, we will consider a fictional account of doctor-patient hospitality in order to analyze a depiction of doctor-patient stakes in healthcare and how the differing goals of the host and guest intensify conflict.

## Mind Games

*House, M.D.* is named for its main character, Dr. Gregory House, a “pain medication-dependent, unconventional, misanthropic medical genius who leads a team of diagnosticians at the fictional Princeton-Plainsboro Teaching Hospital” (Jensen 1). House, who is results- and ego-driven, has virtually no bedside manner or rapport with colleagues, and constantly straddles the line between experimental medicine and malpractice due to his methods. His personal mantra is “Everybody lies,” and he generally treats his patients and colleagues with a mix of disdain and suspicion. For a majority of the episodes, House does not actually interact with patients face-to-face; he has a team of doctors who work under him and serve as his intermediaries, thereby allowing him to dilute his sense of responsibility to individual patients. Instead, he treats them as sets of curable symptom-puzzles. Throughout the series, House is shown to be difficult to work with *and* a difficult host to submit to; the show’s success hinges on House’s brilliance—his ability to use his highly skilled medical gaze to see things that others (including medical tests and advanced technologies), either miss or are not experienced enough to see. British actor Hugh Laurie’s portrayal of House is simultaneously irritating and captivating, leading Jeff Jensen to begin a 2005 article about the success of *House, M.D.* by stating “Hugh Laurie isn’t a bastard, but he plays one on TV” (Jensen). There is a sense that House represents many within the medical profession: determined and intelligent enough to succeed as a doctor, but ruthless in their methods. This ruthlessness is a source of consternation for more ethically-oriented doctors and hospital administrators on the show; in trying to save lives and care for others, it is assumed that the healthcare profession will at least try to put on a good face for its

interaction with the other. But House confound that belief and although he does appear to love some part of his profession, helping people does not seem to fulfill him. He is bound to welcome in the others who need his help, but in entering a hospitable relationship with him, they might find the conditions (the *dealings with* this host) too painful.

House's foil within the show is Dr. James Wilson, Princeton-Plainsboro's head of the Department of Oncology. Wilson is described by House as, "a buddy of mine people say 'Thank you' to when he tells them they are dying" ("Three Stories"). Wilson is dedicated to his patients in a way that House does not understand. He often becomes emotionally invested in his patients' cases, and despite dealing with cancer on a daily basis, is portrayed as a happy, well-adjusted human being. The relationship between characters of House and Wilson was modeled after Sherlock Holmes & Dr. John Watson. In most publications about the series, Wilson is described as the "only true friend" of the misanthropic House; critics of the show wrote that Wilson was the only irreplaceable supporting character within the show and that he should "never, never, never, never" leave (Ryan). The dynamics between the two doctors are complex, but put simply: House is innovative where Wilson is traditional; House takes risks where Wilson follows the rules. This dynamic is well-known to viewers of the show by the time they see "Games." The episode follows a familiar narrative structure: two seemingly contrasting storylines are weaved through, and together, the similarities or differences in the two stories end up allowing some medical mystery to be solved. The show is not a whodunit, but a "whatdunit" in which "germs and diseases are suspects and culprits" (Jensen). Season 4 of *House, M.D.*, including this episode, shows House parting with his original team of three interns. In attempts to replace them, the season sees House force dozens of talented,

accomplished doctors to jump through a never-ending series of diagnostic, professional, and even personal hoops in order to become his new interns. But the games they play are not the focal point of this episode. Instead, in “Games,” the main story involves Jimmy Quidd, an aging, drug addicted punk rocker who wound up House’s patient because he had so many symptoms related to drug use that House was convinced there was something more nefarious going on. The secondary storyline involves a patient who Wilson diagnosed with terminal cancer; upon reviewing new scans, Wilson realizes that the patient does not have cancer at all, and is completely healthy.

When we are introduced to this secondary storyline, we follow House to Wilson’s office to find Wilson not behind his desk, but in a chair in the corner. House enters, peeks behind the door to where Wilson is sitting, enters, and then takes a seat behind Wilson’s desk. In Wilson’s hands are scans and a folder. House asks, “What do you think of Amber?” (00:07:10), to which Wilson replies, slowly, “I screwed up a diagnosis” (00:07:18). House says, “You don’t seem that upset by it.” (00:07:21). Wilson rises from his chair, walks over to an illuminator (X-Ray lamp), near him, and says, “I diagnosed a guy with adenocarcinoma three months ago, told him he had six months” (00:07:28). House: “So now you’ve gotta tell him that he’s way behind on his Christmas shopping” (00:07:32). Wilson ignores this remark, and continues: “He didn’t get worse. I rechecked everything, and the biopsy was a false positive. Harmless lesions, caused by talc inhalation” (“Games,” 7:33-7:46). House responds, “Medical clemency. Interesting.” Clemency is a term typically reserved for legal pardons; clemency is a mercy, lenience, or a forgiveness of sins. It is less common within medical scenarios, but medical clemency is akin to a ‘medical miracle,’ where the patient no longer has to die. Instead of

making a mistake that is going to negatively impact someone's life, Wilson's mistake is one of mercy. Wilson wants House to "just be happy" for this felicitous mistake, but House cannot. As always, he is wary of the human element and is suspicious of sudden pardons. Being given life when one was previously on the brink of death is too good to be true for House, and the happiest of accidents for Wilson.

Within this scenario, the expectations of the players within the hospitable relationship have lasting, significant impact. Wilson's position as the cancer authority (and a master in the delivery of bad news), within the hospital leans heavily on static, structured doctor-patient relationships rooted in a patriarchal type of medicine. Within his hospital, he is the head of oncology and the head host of his patient/guests. While he is a good host, and is careful to help his guests to feel welcome within his domain, he is a host with rigid expectations. So, this occasion—one where he gets to deliver good news—causes him to anticipate at least a heartfelt 'thank you' from his patient. And this expectation is warranted since the audience is aware of his reputation and his skill in the delivery of bad news. For Dr. Wilson, possessing the medical gaze allows him to serve as a messenger between the individual and the laws of nature; he is the ultimate host and his hospital is a place where hospitality's laws to be put into action in the most benevolent ways possible.

When Wilson meets with the misdiagnosed patient, Mr. McKenna, House inserts himself into the conversation as a 'consulting colleague.' The following conversation transpires:

*Dr. Wilson:* I got your new test results back.

*Mr. McKenna:* I know the prognosis.

*Dr. Wilson:* Mr. McKenna, I can't believe I'm able to say this, but you're cancer-free. The biopsy looked like adenocarcinoma, but it wasn't. Harmless lesions on your lungs. You're fine.

*Mr. McKenna:* I don't get it.

*House:* Cool.

*Dr. Wilson:* No, it's, I know this must come as a shock, but, I've double-checked the labs.

*Mr. McKenna:* I just accepted an offer on my house. I've had three goodbye parties. I'm buying plane tickets to Venice.

*House:* You can still use those if you're alive.

*Mr. McKenna:* I have to pay a \$6,000 broker commission on a house I'm not selling. Money I don't have. (Sighs). Thank you, for letting me know. (Gets up and leaves).

*Dr. Wilson:* I would've thought the living would mean more than the expenses.

*House:* It's not about the money. (9:00-10:10)

This interaction illustrates an unexpected turn in host-guest relations. When the host opens up the doors and frees the guest/hostage, the guest refuses. And this refusal is double-edge; in expressing his dissatisfaction, Mr. McKenna refuses to accept the long life ahead of him, and he undermines the doctor-patient, host-guest relationship. Mr. McKenna's experience as a *living dying* person was unique in that he was actually healthy, so he was well enough to achieve goals that he had left undone. When one's future is infinite, then the future self can always accomplish whatever cannot be done today. It is the limitation of that futurity that offers perspective; the perspective produces anxiety and causes actions to happen. In his anxiety, Mr. McKenna had begun to *really* live, potentially for the first time in his entire life. And this new living, in the face of death, had virtually no consequences because Mr. McKenna was not anticipating living long enough for consequences to matter. So in hearing that life is now not just an option, but a certainty, Mr. McKenna's identity as a *living dying* man was called into question, as were his commitments and consequences for his actions while under anxiety's spell.



When Mr. McKenna leaves, Wilson is confused and dejected. His sense of himself as the benevolent host has also been called into question through this interaction. Rather than being a good guest, Mr. McKenna had been, in Wilson's mind, unreasonable. Mr. McKenna's reaction also hints at the type of discipline that most of Dr. Wilson's patients adhere to in their interactions with him; his role as doctor and interpreter of signs within the body causes his patients to respect him and interact with him in a certain way. Mr. McKenna's unhappiness at his new prognosis not only breaks with typical guest-host relations, but also with the idea of the patient's disciplined acceptance and adherence to medical diagnoses/prognoses. Additionally, when given the bio-power and knowledge-power that many other individuals fight for, Mr. McKenna is deeply unsatisfied. He wishes to return to a life of blissful ignorance where his actions are motivated by his limited time and where the worries of day-to-day life are no longer significant.

### **Born to Die**

In contrast to Mr. McKenna's medical scenario is the Jimmy Quidd narrative. Quidd fully embodies the lifestyle associated with punk rock rebellion; he is reckless and has no concern for his own wellbeing. He is admitted after throwing up profuse amounts of blood in a back alley before a show; once he enters the hospital, dozens of other symptoms present, and they are of increasing seriousness, such as when blood clots collect in the tips of his fingers. After House and the other doctors hook him up to an oxygen tank, he sneaks into a bathroom and lights a cigarette—an action that causes an explosion, damages property, and nearly kills Quidd. Minutes later, he resists a procedure because he has plastered one of his arms with nicotine patches and does not want the physicians to find out. Late in the episode, it comes out that he has been sharing needles

with other drug users (00:22:27); he even admits to Amber, one of the doctors in the running to be House's intern, "I'm not an adult. I never wanted to be. So if the choice is running out the clock with a walker or a bedpan..." (00:31:36-00:32:01). "You don't regret anything," a surprised Amber asks him. Quidd responds, "Well, there was a lot of drugs, a lot of drinking, a lot of fights. I regret everything else. You hate me, don't you? I don't care...it means you have no regrets" (00:32:07-00:32:46).

House, who rarely speaks directly to patients, spends time with Quidd and asks him about his music, which is a cacophonous, raucous, and difficult to listen to collection of stops, starts, and screeches. Quidd pushes back: "I don't do it for you, I do it for me" (00:24:47). House refuses to accept this, telling Quidd that, "There are three choices in this life: be good, get good, or give up. You've gone for Column D. Why? Simple answer is, if you don't try you can't fail. You really that simple?" (00:24:50-00:25:09). Quidd responds: "Some people, they like my music, but most people can't stand it. They just sort of just shrug and ignore me, but a few, they feel like they have to tell me what I'm screwing up, what I'm wasting. Why do they care?" (00:25:10-00:25:35). As opposed to Mr. McKenna, Jimmy Quidd's way of life violates the laws of hospitality. He enters into the hospital/house, and at every turn, attempts to kill himself to spite the host. What's more, he also wants to burn the house down in the process. Frustrated by his resistance while trying to provide him with life-saving treatment, Amber admits to House that she hates Quidd because of his drug addiction, and feels that he is "throwing his life away" (00:14:20). House presses her on this, saying, "Why? Because he's setting his own terms? Not living in fear of every pop quiz?" (00:14:20-00:14:28). Amber and House then engage in a discussion of happiness: she believes that winning and living within the

rules are integral to achieving happiness, and her disdain for Jimmy Quidd's inability to be a proper guest is tied to her perception of his actions. Someone that reckless and that drug-addled cannot possibly be happy. But this is Amber's worldview, not necessarily House's. House reminds her that their patient *is* happy. "He's an idiot," she retorts (00:15:01). But House hopes to complicate this, possibly because of his own abuse of painkillers. "There's something freeing about being a loser, isn't there?" he asks Amber (00:15:07). This is a rhetorical question worth considering. For medical professionals tasked with saving patients' lives—hosts obligated with the safekeeping of guests within their domain—rebellion from the patient makes the job more difficult, even impossible. The standards of interaction, the modicums of respect that are guaranteed within the relationship are ruptured, and what is left for the host is a deep concern over power. If patients/guests do not feel an obligation to obey or to, at the very least, comply, the dynamics of the laws of hospitality become strained. They, too, turn into something strange, something more accurately described as *hostipitality*. But even *hostipitality*, that hostility-hospitality struggle, falls short. In subverting the hospitable relationship, patient/guests reject the doctor/host and the power of the gaze. They become unshackled from the hospitable relationship and its requirements; the unknown of that freedom is what is troublesome to those whose status and identities are deeply rooted in a controllable hospitality.

For Dr. Wilson, his shaken identity as the good doctor only grows worse when an attempt at reparation is made. Because Dr. Wilson feels guilt over Mr. McKenna's reaction (one that he wrongly predicted, one that left him feeling as though he had failed in the performance of a good deed), he later attempts to financially compensate Mr.

McKenna with an accompanying ‘liability release form’ in order to correct his wrong diagnosis turned right—an overcorrection in every sense. House knows his friend, and confronts him before he can go through with paying off his patient. House shouts at Wilson, “You’re gonna pay the guy the six grand, aren’t you? There’s no negligence without injury!” Wilson replies, “I handed the guy a death sentence!” to which House responds, “He’s not distressed with the death sentence, he’s distressed with the life sentence.” Wilson’s guilt, though, is larger than his ability to see the logic and the lack of real harm done. He tells House, “I gave him three months of misery.” House is careful to point out to Wilson that this is not true: what Wilson did was give Mr. McKenna an illness and a timeframe that forced him to live, that made him “special”; Mr. McKenna’s anger stemmed from releasing him from his diagnosis, giving him his old humdrum life back, a change that effectively “made him boring again” (18:00-19:00). For Mr. McKenna, being confronted with the finitude of life creates opportunities for significant personal agency. As it is portrayed in the episode, death gave Mr. McKenna something to live for, and a sense of urgency for his accomplishments. While it also released him from the obligations of hospitality, that was of secondary interest to him. The freedom he had never had before, and cherished in his status as a *living dying* man, was the freedom to live with intention. He had finally said all that he needed to say, done what he needed to, and unleashed himself from the obligations of a mortgage and a job and relationships that left him wanting more. In cluing him in on his mortality, Wilson provided him with a timeframe in which to harness his anxiety in *being-towards-death*. In removing that, he rendered Mr. McKenna’s anxiety impotent, directionless, and purposeless.

Purposelessness is an endeavor that Jimmy Quidd calls his “purpose.” As opposed to Mr. McKenna, Quidd is unafraid of consequences, and welcomes opportunities to push the limits of his Being and the grace and generosity of the Other. In a sense, his actions welcome annihilation of the self. Everything he does propels him into a state of *being-towards-death*. More so than other manifestations of Being, an individual as reckless as Quidd embodies the risks associated with unconditional hospitality. Derrida warns of the dangers of unconditional hospitality because without boundaries, each party is completely vulnerable to threats from the inside. Quidd does nothing to protect his body or his Being, and instead welcomes in all threats—all drugs, all violence, all high-risk behaviors. He is simultaneously the worst possible landlord/host for his own body and being and a terrible guest in the larger scheme of society. His motivations are purely the satisfaction of his addictions...or so the doctors under House’s supervision assume (00:20:00). What they find is that Quidd cares for no one and nothing *except* abandoned children, children who no one else wants and who have a worse existence than Quidd. He routinely volunteers with and attempts to entertain these forgotten children, and it is this close proximity to them that gives him the measles which have made him so sick. If he had taken care of his body/house, the disease would never have penetrated his body’s natural defenses. But his lack of investment in his own being invites illness in, making it at home within him and encouraging it to take root. This is his only redeemable quality: his desire to make the circumstances of those less fortunate than him better through human connection. And it almost kills him. In another sense, though, this unconditional openness to the Other allows him to connect more meaningfully to those around him.

While there is a risk inherent within that connection, it is one that Quidd is willing to take.

The reckless aspects of Quidd's personality that make others so uncomfortable are easy for him to bear; there is no being-at-home for someone who burns their own home down, and Quidd accepts this. Wilson, however, cannot. In their final interaction, Wilson follows through in his attempt to compensate Mr. McKenna for the false diagnosis. The following interaction takes place:

*Dr. Wilson:* I can't apologize enough—to you, to your family. There may not be any technical liability here, but...

*Mr. McKenna:* (Tears up Dr. Wilson's check)

*Dr. Wilson:* You're ripping it up because you think it would be wrong to take money from me?

*Mr. McKenna:* I think it'd be wrong to take so little money from you.

*Dr. Wilson:* You're out \$6,000...

*Mr. McKenna:* You ruined my life.

*Dr. Wilson:* I ruined your three months.

*Mr. McKenna:* For the first time in my life, I was living in the present. 'Cause that's all it was.

*Dr. Wilson:* You're suing me, not for the wrong diagnosis, but for the right one? Have you spoken to a lawyer?

*Mr. McKenna:* You gave me happiness, and then you took it away. (Gets up and leaves.) (00:26:11-00:26:57)

Dr. Wilson's overwhelming sense of response-ability prevents him from being able to simply let the situation play out naturally; he must find a way to control the uncontrollable. This is ironic because his status as a medical professional allows him to diagnose without requiring that he remain involved for the psychological and emotional tailspin his diagnoses leave his patients in. It is his desire to provide high-quality care that keeps him invested long after he should remove himself from the situation. As the main controller in most diagnostic situations, Wilson's inability to either predict or control Mr. McKenna's perception of this new diagnosis places Wilson in the hostage position. He

cannot believe that he is not being treated as he is always treated and, more than that, that his good intentions are not being met with the standard appreciation. This is one of the negative side effects of Western biomedicine's history of being patronizing towards patients. Wilson approaches Mr. McKenna in order to reset the host-guest relationship; if Wilson can get Mr. McKenna to let him off the hook, then he will not be held responsible and can go back to being the 'good doctor'. For possibly the first time in his career, his guest, a guest that he cannot seem to please or to make at-home, holds Wilson hostage. His drive to 'fix things' is really an attempt to provide his guest-turned-host with a type of justice—or at least monetary compensation—that is in line with McKenna's new moral code and which will allow them both to return to their previous roles. When Mr. McKenna rejects the offer because Wilson had taken away his "happiness," a bewildered Wilson defends his attempts at recompense, telling House, "I'm trying to take responsibility" (00:33:42). House responds that by intervening and not allowing Wilson to pay McKenna, House is "trying to teach [Wilson] that everyone is out for theirs and you might as well keep yours" (00:33:48). "You have to control everything!" Wilson shouts at House. The two argue about these mechanisms of control that they each battle with in their role as healthcare professionals. But their coping styles are more an aspect of their personalities than their professions. "You wanna know why you offered that guy six grand? You think you can cure pain," House tells Wilson. "Life just happens," Wilson tells house, "and it scares the hell out of you. You think you can avoid pain!" (00:34:28). As they argue, Wilson finally tells House, "You don't want to face it any more than my patient does: Dying is easy. Living is hard" (00:34:33). There is a pause in their conversation, and the two doctors stand, looking at one another. House speaks first: "That

can't possibly be as poignant as it sounded" (00:34:38). Before they can continue, they are interrupted by more extreme symptoms from Quidd, and both men leave the room to "do their jobs" (00:35:21).

### **The Ethical Turn**

The purpose of this project is to examine the 'good death,' and the factors that can inhibit individuals from attaining one. The rules and regulations of Western biomedicine play a significant role in these permissions and limitations, but as this project has argued, it is face-to-face human contact that complicates end-of-life. When someone who is other to us recognizes our suffering, that suffering becomes at least partially the other's responsibility. This is the same responsibility that doctors willingly take on when entering a profession that is constituted by the responsibility of face-to-face encounters with patients. "In medicine, doctors can do far more than they could in the past. They can do interventions that were unimaginable a few decades ago. Every time you give those kinds of power they come with difficult situations and tough ethical choices" (Murray qtd. in Kane). In terms of ethics, Americans view Western biomedicine as a ready and able agent in whom to place not only their faith, but their control. This giving-over of control, which is essentially a giving-over and opening-up of the self that invites violence, ruptures patient agency. For advocates of increased end-of-life options, this desire for increased agency is the intangible worth fighting for.

But as this chapter has shown, there is an alternative even to this understanding of end-of-life. In this particular episode of *House, M.D.*, the insights into doctor-patient, host-guest relations are easily accessible and provide thoughtful viewers with an occasion for encountering different points of view. In end-of-life encounters, insecurity of the self



is prevalent. What is troubling is that, “In any institutional setting individuals may be unusually insecure, and unfamiliar surroundings with unknown personnel and routines will almost inevitably impinge upon a person’s ability to act as an autonomous agent. In situations involving medical care, illness, lack of understanding, and fear may compound and intensify these insecurities” (Biggs 99). The laws of hospitality govern our experiences as patients within the hospital’s structured setting, and provide us with a set of behaviors that will help us to achieve our goals. These experiences are made strange by our unfamiliarity with the hospital as an institution, and this has long been considered the primary source of patient dissatisfaction. Simply put, patients have no power and doctors have too much. But as “Games” illustrates, this typical hospitable structure is complicated when doctors who are used to serving as hosts find their authority challenged; in not accepting the doctor’s word as law, patients throw off the laws of hospitality and plunge both doctor and patient into a hostility struggle. This is a generative struggle, though, since it provides both parties with introspection and opportunity to reconstitute identity—either their previous identity, or their newly discovered one.

The layers of control within “Games” allow for a more nuanced analysis of this struggle, and yield surprising results. First and foremost, “Games” puts the volatile nature of contemporary healthcare on display. While not all health emergencies are ones that will wind up in front of a team of diagnosticians, as patients within the hospital setting, the bodies figuratively and literally “opened up” before the eyes of medical professionals are vulnerable. While healthcare professionals might like to consider their work scientific and measurable, medicine is messy and unpredictable. It is not a perfect science, and its

practitioners are all too human. For the terminally ill, their vulnerable hospitality is necessary in order for suffering and pain to end. In opening-up and asking for assistance from their hosts, they can shift some of the responsibility for their suffering onto their doctors. Vulnerability allows for the host-guest, doctor-patient relationship to work. But for doctors, this vulnerability puts tremendous responsibility and pressure upon their training and expertise. In these instances, the medical gaze must not fail—meaning, the healthcare professional in possession of the medical gaze must consider himself infallible in order to perform the duties of his job. The gravity of the situation is not taken for granted by either party. In good health and poor, both parties are held hostage by expectations and by their sense of responsibility. “Hospitality is opposed to what is nothing other than opposition itself, namely, hostility...The welcomed guest is a stranger treated as a friend or ally, as opposed to the stranger treated as an enemy (friend/enemy, hospitality/hostility)” (4). The relationship between enemy/friend, hospitality/hostility, represents a blurring of the fluid boundary between the two, “hostipitality.” Derrida states that, “hospitality is certainly, necessarily, a right, a duty, and obligation, the *greeting* of the foreign other as a friend ...on the condition that he maintains his own authority in his own home” (4).

But in “Games,” no one has any authority within the hospital. Wilson, House, Mr. McKenna, and Jimmy Quidd are all locked together in an endless struggle between hospitality and hostility. So, in addition to illustrating the struggle of medical professionals in providing adequate care, “Games” forces us to consider our position as hosts and that position’s potential for violence, or, its inherent capacity for turning into something strange and rendering us hostage. Derrida stated that, “I am the hostage of the

other insofar as I welcome the face of the other, insofar as I welcome infinity. For Levinas the welcoming of the other is the welcoming of an other who is infinitely other and who consequently extends beyond me infinitely,” to the extent that “when I consequently welcome beyond my capacity to welcome. In hospitality I welcome an other greater than myself who can consequently overwhelm the space of my house” (17). And it is this overwhelming quality of the other, the other who will not behave, that is at work within “Games.” In addition to this capacity for violence, “Games” allows us to interrogate the ‘good life,’ a stone left undisturbed in this project, but a stone with overturning here. It is easy to accept that the ‘good life’ is equated to actually being alive, and to having a sense of one’s life as a “futura without horizon,” as Derrida called it (“Hostipitality”, 17). For most, the ‘good life’ is constructed by the individual’s pursuit of the good and the virtuous. In connecting with Others and treating them not as strangers, but as welcome friends, individuals inch closer to this ‘good.’ But there is a sense that the ‘good life’ is something to be chased and never caught; it, too, is an impossibility. The struggle towards it is an admirable one in that it is focused on the ethical treatment of humanity. In turning towards the other case studies featured in this project, an image of the pursuit of the ‘good life’ emerges: it is one that is lived alongside and for the betterment of others; it is one that includes adventure and education; it will allow one to be ‘sung out’ in the event of death.

But there are those for whom the call of the conscience is unsavory. These are the ones who struggle against the living-for others. The patients within “Games” are each caught in a different kind of responsibility, which Levinas referred to as a “traumatic hold”; for Mr. McKenna, the trauma resonates from returning to a life that was unhappy

before diagnosis, and is now completely disrupted by his not-dying. For Jimmy Quidd, his reckless behavior has somehow made him immune to death; it is his immortality that causes trauma. Together, these narratives allow for a theoretical turn, and force us to consider whether life might actually be the most traumatic hold of them all.

### **Worth Living For**

If being given life is not enough to make hospitality satisfying, then what is? Davis explores how the notion of *being-towards-death* in Heidegger, Levinas, and Derrida is an integral component of the hospitality offered by the Dasein to the Other. She writes: “Heidegger is clear that Dasein names (a) being that is first of all in-the-world and with-others—‘world’...being always a ‘shared world’” (Davis 90). The concern over the shared world is also a concern over identity—over the delineations of the Dasein, or Being. Because in sharing the world with all the Others, the individual is required to endlessly answer and respond to the call of the Others. In these confrontations, hospitality forces Dasein to “relate to other Daseins and objects” (3). But there are factors that can complicate the repetition of the call and answer. Death is one of them; “The time necessary to such self-awareness is obviously most crucially perceived in the advent of one’s own death. *The fact of dying for and by ourselves is what gives the self authenticity, making it a ‘being-toward-death’*” (3, emphasis my own). So, recognition of Otherness is also necessarily the recognition of the similarities between the self and all Others, and as such, a recognition of the completeness—and the possibility of end—of the self. Self-awareness is a part of identity formation, but it is most prevalent in situations where the self becomes held hostage by its own finitude. Death forces the Dasein into self-awareness.

Recognition of death pushes us to “reach absolute authenticity in an ecstatic being-toward-death,” revealing “less a sense of alterity than the area in which I come into what is absolutely and precisely mine, mineness” (3). And this mineness reveals the individual’s limitations and their unique, singular existence. In “Games,” what is offered to Mr. McKenna is an authenticity in dying. Heidegger refers to this “as the end of *Dasein*” and claims that this kind of “death is the most nonrelational, certain and as such, indefinite and unsurpassable possibility of *Dasein*. As the end of *Dasein*, death is in being of this being towards its end” (*Being and Time* 245). So, while the individual can attain a *being-towards-death*, all of the Others who come into contact with him cannot fully relate to it. Death creates a barrier between the living and the dying, and in practical terms, has a way of removing the *living dying*’s support system.

Per this definition, “death is explained as the end of *Dasein*, through which *Dasein* comes into its completeness. The end of *Dasein* implies that *Dasein* is not in the world any longer...death is not a fixed point in the horizon of time, but is a living process that awakes and reawakes constantly the original consciousness of time in man” (Tangjia 144). Death awakens Mr. McKenna to the possibility of life—and thrusts him into the action of being alive. For the first time, it seems, he is exercising agency in his decision-making and acting of his own volition. The energy fueling this burst of life and agency is finite, though, because it is confined by his imminent death. Death has separated him from the herd, made him special. He cannot possibly go on living as though he were dying; he has neither the capacity nor the identity as the *living dying* subject to fuel him. Jimmy Quidd, on the other hand, is all energy and no thought. He is entirely being-

towards-death; his life is all mineness, all the time, and as such, it is empty of meaningful connections and relations. He cannot stand to be under the gaze of the Other; the face-to-face renders him too vulnerable, and causes him to pause in his quest for being-towards-death. Where Mr. McKenna finds reasons to live, Jimmy Quidd finds boundaries preventing him from achieving death. Mr. McKenna's identity is shattered by his prognosis and then re-prognosis; Jimmy Quidd's identity is virtually nonexistent already, since he lives with the purpose of not living, not making connections, and not producing meaning. In considering the distinctions between these two men, a phrase from Zoe FitzGerald Carter is helpful: "People die the way they lived" (246). The fact that neither Mr. McKenna nor Jimmy Quidd achieves death suggests that they had never really lived.

## Chapter Seven

### Conclusion

*A narrative achieves closure when its elements come to fit together in a pattern that extends over time and that confers a distinctive significance to those elements. But the completion of the pattern—the closure that is reached when all the elements are properly fitting into place—does not have to bring the narrative, and what the narrative describe and explains, to a temporal stop.*

--Luca Ferrero, "Agency, Scarcity, Mortality"

In "Critical Rhetoric: Theory and Practice," Raymie McKerrow writes that a critical rhetoric "seeks to unmask or demystify the discourse of power" (92). In order to accomplish this task, a critical rhetoric must piece together "disparate scraps of discourse, which, when constructed as an argument, serve to illuminate otherwise hidden or taken for granted social practices" (92). This project has done precisely this work of collecting and arranging in the hopes of developing a critical rhetoric of end-of-life. If some patients in Western biomedicine are receiving more lenient conditions during their hospital visits—the option to refuse medication or treatment, the right to withdraw life support—then it seems that other permissions might be possible. In order to propose a starting place for increased patient-centered care, this project pulled together a variety of discourses, including ancient philosophical texts, documentary film, popular media, and fictionalized medical television. From these disparate scraps emerges an understanding of all human interactions as being rooted in hospitality, a pre-ontological recognition of the countless others who surround an individual and to whom an individual is responsible. What becomes apparent is that while normal instances of hospitality often successfully protect both the sovereign host and the dependent guest from a violence which is always possible, when individuals encounter unanticipated and therefore abnormal situations, their needs change. These changing needs do not necessarily persuade the host to alter the

conditions that were placed upon the guest at the beginning of the visit. Rather, these conditions create conflicts within the host-guest arrangement. In asking for added permissions, the guest runs the risk of overstepping the invisible boundaries that have allowed for him to be a guest at all. This thrusts the guest into an unknown territory—a space where all moves come with tremendous risk and where the hospitality relationship could be undone at any time. For the host, unforeseen changes in the identity or status of the foreign guest change the dynamics of the relationship in a different way. If the host is uncertain of the ways in which the guest has been altered, it becomes more dangerous to provide shelter. What if these new changes bring about a violence that shatters the precarious hospitality arrangement?

Hospitality undoubtedly plays a role in these pre-ontological evaluations of risk and reward, hospitality and hostility. Through the encounters the individual experiences otherness and singularity, recognizing its individual limits and the face of the other simultaneously. But hospitality is also seen on larger scales, where power is dispersed in such a way as to become unfocused and not completely discernable. This is especially true in Western biomedicine, where the overarching industry of medicine is the ultimate host and its healthcare workers/agents and patients are all guests with different rights to different kinds of experiences. In performing their roles on behalf of the hospital, healthcare professionals inhabit a fluid position as guest of their industry but host to their patients. From this position, they can greatly benefit and ethically care for those seeking treatment and comfort. But in situations of terminal illness, the guest offers the host a limited hospitality: *I am dying, but will you let me come in so that you can watch?* This hospitality does not protect the host from the violence of being near death, of having to



dwell under the same roof as death—nor does it prevent the ethical preoccupation with death that shapes one’s views on mortality and morality. In fact, in asking to be welcomed in by the host, the terminally ill guest is asking them to be open to this kind of emotional threat and a hospitality that is imbalanced from the outset. For hosts who work on behalf of industrialized biomedicine, the reaction to this invitation has long been to place boundaries on the patient and to require that the patient enter and keep trying to live. This imbalance does not mean either group’s request malicious, but it does prevent the medical profession from ethically engaging with patient concerns and acting upon those experiential needs and wishes that patients share. For the medical professional to be the best possible host, those individual needs are often sublimated in favor of rationality and objectivity. In its current iteration, Western biomedicine is caught in a rigid hospitality that, in trying to function, has forgotten the ethical imperatives that allow it to act as host in the first place. There is currently no real discourse with which to discuss the general subject of death and dying or the more specific instances of terminal illness that serve as case studies in this project. This lack of discourse has not come about because death is not happening; instead, it has become commonplace because the hospital-host is unwilling to discuss it in any real way. In refusing the discussion, or rejecting the call of the other, Western biomedicine has left its guests with no other viable option for attaining the conditions that they desire: if they want to receive the right to die, they will need to rupture the current conception of hospitality and force a renegotiation of conditions. The success of society is dependent upon the “populations,” which represent a cumulative bio-power that moves society forward as it gives it structure (Britt 211). Bio-power is constructed by these masses, and because of this, it determines the “success or failure of

governments, countries, or species,” institutions that offer individuals protection in return for allegiance. Change can be effected if members of society’s populations become more open in their discussions of death and more demanding of certain conditions.

In negotiating for a more dignified, hospitable death, end-of-life and right-to-die advocates are seeking institutionalized recognition of their rights. McDorman writes that when addressing the right-to-die, “the law has frequently granted the uncommunicative, vegetative patient subject status while denying agency to competent, terminal individuals. While such a construction is consistent in maintaining order and control over the body,” this approach is actually counterintuitive within a contemporary society devoted to individualism and control over one’s own life (268). McDorman suggests that the deeper motive behind these rulings is tied to the state’s sovereignty over its subjects: “at issue is not actually the vegetative patient but the state’s ability to exert controlling authority over the life—and death—of the active subject. The vegetative subject can be granted rights, without compromising the state’s power, because he/she lacks the direct means for their exercise” (269). Within the context of hospitality, this means that the states provide non-active agents with dignity at the end-of-life primarily *because* they are not active, meaning that the state cannot be held accountable for *violence* towards the vegetative individual. The host’s intervention in the form of removing life support releases them from hospitality more quickly than if the patient was to linger and require support from the state. In granting these rights to individuals who cannot, at the time they are granted, either request them or assure the host that the rights are desired, the state values its obligations to the non-threatening guest over those of its more autonomous, response-able ones. “That the incompetent could be filled with agency while the competent is rendered

powerless reveals the reach of the state apparatus” (269). Unless the state empowers the position of its competent but vulnerable citizens, it is not acting ethically. It is, instead, protecting its own sovereignty at the cost of the rights guests who are in indispensable part of the bio-power that makes up the state in the first place.

In opening up to death by more closely examining its place in American culture and providing many different perspectives on end-of-life, this project hopes to guide its readers through their own processes of consideration and discovery. It is unfortunate to think that there are only two approaches to end-of-life for the terminally ill: either an unattainable standard of rationality in the face of a death that feels unfair, or a slow and unending suffering that slowly robs individuals of all of the experiences that individuate and singularize them. While the activism in the state of Oregon can be seen as an aggressive push against the state’s sovereignty, it is actually a more compromised hospitality. The Death with Dignity Act provides Oregon citizens with the knowledge that their deaths do not have to be either fully rational or filled with physical agony. Instead, the Death with Dignity Act offers control and a backup plan that is ‘in reserve,’ but in no way mandated by the state. Those who taken advantage of this plan have removed themselves, already, from the structure of Western biomedicine. Oregon’s law has been successful thus far because it balances its responsibilities to citizens with its sovereignty as a state; the state carefully evaluates the patients who seek out the Death with Dignity option and monitors whether they eventually consume the medications or not. The Death with Dignity Act ensures that in their dying, they can effectively achieve the act’s purpose and do so in a way that dignifies and values human life rather than robbing it of its agency.

The fact that Brittany Maynard had to disengage from her lifelong hospitable arrangement shows just how determined the terminally ill are in dying in a dignified way. Maynard's end-of-life blends the two competing human urges that Socrates locates in distinctly different parts of the body in Plato's *Phaedo*: reason and desire. Maynard made her decision after having received all of the information, and having weighed her options. In her analysis of the situation, dying on her own terms was more ethical than allowing herself to linger indefinitely in a body that her soul no longer inhabited. If the purpose of living is philosophical exploration, then Maynard accomplished that when she made the well-reasoned choice in departing before she would become a fully dependent, out of control guest. In a vegetative state, she would be putting her fate in the hands of loved ones who she did not want to incorporate into the very difficult predicament she found herself in. Instead, she negotiated for her own terms and found a legal option for ending her suffering.

This project is not solely invested in the type of death made possible by the Death with Dignity Act. Instead, it is invested in following in Oregon's footsteps. One of the main ways to extend the reach of the conversations happening in Oregon is to engage in discussion and to listen to the experiences and concerns of the terminally ill. Medical professionals dealing with end-of-life cannot remain the only members of society who are actively listening to the experiences of the terminally ill. It must become a concern of healthcare on a much larger scale, since "The importance of team work in end-of-life care cannot be stressed enough. On-going dialogue between the professionals involved in patient care strengthens what each individual professional has to offer" (P. Miller 41). "Ideally, the most successful team work is when all members contribute to the plan of

care in a way that honors each professional and allows for coordinated service to help patients die in the way they choose” (41). Progress in end-of-life care in the United States can only be realized if more than a handful of states begin taking pains to revisit their current methods.

According to P. Miller et. al., “Conversations can build bridges, heal wounds, and create understanding and meaning for both patients and [healthcare] professionals alike” (41). And this kind of compassionate, dialogue-oriented care is only made possible through “experience, education, and commitment over time” from all involved parties (41). In one respect, healthcare professionals are responsible for offering these kinds of conversations to patients; in another, it is the patient’s responsibility to demand more thoughtful, individualized end-of-life care. But neither the individual nor the institution of Western biomedicine can accomplish its goals if it takes on or rejects full responsibility. The burden, then, is on both parties to participate and weigh the full range of available options with care and compassion. In providing not just adequate but *dignified* end-of-life care to all Americans, Western biomedicine will provide its citizens with access to a more compassionate kind of death.

Conversations about end-of-life and the process of dying are necessary not only because of the ethical necessity to provide individuals with a full understanding of their options, but because of the shifts in population that are currently happening. It is extremely likely that most Americans will experience a serious health concern during the aging process. Confronting one’s finitude has other benefits, too. In confronting our future, individuals have the opportunity to examine the “horizon of temporal identification” and to rid the self of “pressures (both motivational and rational) toward

temporal integration” of the self (Ferrero 355). Instead of waiting for a future that may self that never be realized, this identification allows for individuals to become their future selves now, or to at least embody a more fully realized synthesis of the future and current selves. “Very distant selves might be taken to be outside the reach of one’s present commitments, projects, cares, and values,” but giving these imagined present selves some consideration provides the individual with a chance to think about not only what they wish to accomplish before there is no longer time, but how they want death to play out (357). Recognizing the end of life as a set of opportunities rather than a death sentence can alleviate some of the anxiety affiliated with those obligations, and allows for a more thorough understanding of one’s identity and legacy.

Simone de Beauvoir writes in *The Coming of Age*: “We must stop cheating: the whole meaning of our life is in question in the future that is waiting for us. If we do not know what we are going to be, we cannot know what we are: let us recognize ourselves in this old man or in that old woman” (4). In this recognition, we enter into a hospitable relationship with that future self—the future self that, at some point, will be in need of our compassionate consideration. This offering to the future self allows us to “take upon ourselves the entirety of our human state,” and “when it is done we will no longer acquiesce in the misery of the last age; we will no longer be indifferent, because we shall feel concerned, as indeed we are” (5). Spending time in calm consideration of that old man or old woman who we will eventually become is an act of hospitality in which we provide ourselves with unmatched agency. Thinking about old age and the infinite selves that old age could reveal to us readies us for a time when we must be good hosts to whichever self is made manifest. So much of end-of-life is dependent upon receiving

permission, or a 'call' back from the Others who we have spent our life answering and calling out to. In order to put everyone in the best possible situation for making decisions about death in the face of death, Western biomedicine must foster a space in which members of Western culture cannot cheat themselves, and cannot cheat death.

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