"THERE AT THE BRIDGE": ORAL HISTORY, VIRTUAL REALITY, AND
ENCOUNTERING DEATH IN AMERICA

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Introduction

"*Death must be viewed as a mystery, not a problem.*" -Peter Steinfels

Life's inevitable end, death, has always puzzled and frustrated humankind. Why should we have to leave? Dying is an enigma with no answer. It is to be avoided. It is part biological process and part social construct. Medicine works tirelessly to tame it, though it inevitably fails. It dissects, catalogues, and treats its causes—oftentimes staving off final oblivion by the sheer strength of the machines that circulate food, water, and air into our stomachs, veins, and lungs should we ever reach such dire straits. The significance of our technological advances is unquestionable—many precious lives have been saved. Nonetheless, our intentions to save often do harm. From blurring the lines of death and life to increasing the quantity of one's life whilst decimating the quality, in even a brief study of American death culture it becomes clear that we pay a high price for rejecting as abominable a process which may be one of the most natural. This project is in response to the state of death in America.

It began as I stumbled towards the intersection of three very different enterprises: the study of aging and end of life, a cursory interest in virtual reality, and a deep love for people's stories. As I explored, a way to put these things in concert with each other emerged (ever so slowly). The idea behind the final product eventually became the use of virtual reality as a way to present oral histories. These oral histories are about death and dying and they confront their audience with a take on death that defies our cultural status quo by speaking openly and honestly. I hope that the combination of oral history and immersive virtual reality results in

authentic performance of narrative where all the pain and sweetness, grit and gloss, and tears and laughter might emerge with the all of the frankness and phenomenology implicit in the human experience. The thought that is operating behind this virtual experience will comprise this paper, but at the end of the day, it is most important that people share experiences with other people in a way that is as free from affectations as it can be.

In this paper I will outline the public-facing virtual reality experience mentioned above, substantiating the need for storytellers at the end of life and the efficacy of oral history and virtual reality in giving those storytellers a platform. Next, I will examine the state of death in our culture and argue that ignorance and silence about death stem from our cultural moment and contribute to the poor end of life experiences that most Americans face. In the third section I will discuss medicalized dying and how a biomedical death paradigm also detracts from the individual patient's experience of dying. I will discuss how the convergence of a death-avoiding culture and advanced medical technology opens up space for the hospital room of the dying to be a site in which power operates upon the body, and I will argue that individuals can be re-empowered to die on their own terms by increasing their familiarity with death and discussing death with their loved ones using tools like death narratives and virtual reality to catalyze that familiarity.

As death and dying is discussed in this paper, a certain kind of patient will emerge. This dying patient is in the hospital with stable vital signs, but lacks the ability to assert themselves or experience a meaningful life. Sharon Kaufman defines this patient as being in the "zone of indistinction" (273). It is often unclear whether

they will recover a meaningful life or not. They may have arrived at this state due to an aging body or an unfortunate crisis and a predilection for clinging to life at all costs with no stop-gap measures in place to free them from the life-prolonging technology. This predilection, though definitely cultural, may or may not be their personal choice. In all likelihood, they've never spoken with anyone about how they'd like to live at the end or how they'd like to die. In any case, they have taken a journey towards death through murky medical waters and are now kept alive by machinery with little hope of ever regaining their independence.

Although this state is typically not sustained for months or years, it can be. The threshold between living and dying has widened considerably due to advanced medical technology. Not many would wish this kind of death for themselves or their loved ones, who can neither really say goodbye and begin grieving nor can they share a life with the patient as they once did. Families feel the loss of their loved one deeply when they visit, but feel guilty if they do not. This is the patient that we hope not to be, although all of us are vulnerable to becoming if we do not take preemptive action. The idea behind dying well and crafting an intentional death narrative for yourself is so that you do not become a case study, a traumatic memory, or a person whose legacy is tainted by medical bills. Besides the voided life experienced by the brain-dead and comatose who are stabilized, the physical reality of end-of-life in the hospital is inimical to happiness and flourishing. Let's briefly consider the process and consequences of "plugging in" to a breathing machine.

The initial attachment to a temporary breathing tube usually happens in chaotic moments at the hospital when a patient suddenly has respiratory distress.

And, indeed, it is always better to err on the side of saving a life if their preferences are not known. Nonetheless, Dr. Jessica Zitter calls this simple act of life prolongation "a path from which deviation is almost impossible," and for those who don't know they may be nearing the end, it could be "the first stop on the end-of-life conveyor belt" (81). Temporary breathing tubes can last about two weeks before they need to be either removed or changed over to a permanent breathing tube: otherwise, fragile tissues in the trachea will begin to be damaged by the pressurized balloon which stabilizes the tube. If the patient or their family elects to have a permanent breathing tube put in, the patient undergoes a procedure which involves an incision at the Adam's apple, a tube directly inserted into the airway, and a strap around the patient's neck to hold it in place. The side-effects are multifarious:

> Patients on life-support machinery often require arm restraints so that they don't pull at the tubes and catheters. They become prone to recurrent infections in their lungs, bladders, kidneys, and skin, due to the many plastic tubes inserted in various locations that shuttle bacteria into places where they shouldn't be. (82-83)

Besides the mere physical distress of existence on life-support, other factors begin to accumulate. The medical developments, not to mention the emotional weight of the journey to get to this point of stability are heavy: how could we think of compromising all that work by giving up? These aren't the only factors, though. Although it's gauche, money also plays a big part in this experience. Chaplain Brian Cornell put it this way during our interview:

So they come in and something happens to challenge their health in such a way that they don't know it yet but they're not going to leave. But because they don't know it yet, they start stacking the financial things, because, first off, they want to live. We're all trained to thrive. Then maybe they stop, but someone else usually cares enough about them to say, 'Well, we could do a little more. We could do a little more.' If there's a 2 percent chance, isn't someone's life worth any value that we can throw at it? How do you ever put a financial line up against it? With healthcare being what it is, it's a crapshoot. You don't know what they'll pay for necessarily ahead of time or not. So the system doesn't even work with you, so you're throwing on things that say, 'I'm going to do this, I'm going to do this, because this is the person I care for the most. Why won't you live for me?' They die and the debts need to be paid, and they're ankle-breaking debts. They are numbing debts. There's nothing left for the family to receive as a blessing. Or instead they might be given points for things they would have like to have preserved that are valuable, are sold to liquidate to care for the last bits of the family. That is stealing from not just a generation but the next. (Interview with Brian Cornell)

Undoubtedly, the larger consequences of allowing a breathing tube to be inserted are impossible to consider fully at a critical care moment in the hospital. They beg careful consideration and reconsideration as we open and close life's many chapters. These larger consequences beg us to broach a cultural taboo and consider the worth of our lives and the price of staying alive before we ever near that zone of indistinction.

The Listening Room

This paper accompanies a virtual reality oral history listening room. Entitled "'There at the Bridge': An Oral History of Death and Dying in America," the listening room is a virtual reality experience that gives its users the opportunity to confront death in an immersive environment. The oral histories themselves are divided into short, relevant clips that the user can select by interacting with a brief pull quote taken from that section of the narration. Upon selecting a clip, users are virtually transported to a gravesite where they can explore the "perspective of the dead" (or the perspective of a gravesite visitor) while a narrator relays their story in the background. I chose to juxtapose graves and stories of death and dying to force a consideration of the kind of afterlife one might leave behind.

I use the phrase "the perspective of the dead" to invoke the disembodied view of the world that these virtual reality photos occupy: it is meant to provoke thought and feeling, not represent any kind of zombie-esque first-person experience. Although the specific viewpoints taken by the photos are often more like that of a cemetery visitor, in virtual reality, we are not quite ourselves, not quite "there" in the sense of our full identities. Additionally, if you look down in "There at the Bridge," you will not find any human physical presence to "place" you within a virtual body. This non-physical occupation of gravesites creates a kind of being with the dead. The high resolution photos capture the graves of many eras. By experiencing the freshly turned dirt of fresh graves to burial sites over a hundred years old, ground-level close-ups to overlooks from the branches of nearby trees,

the user is forced to confront what the afterlives of the dead look like as they quietly occupy the land of the living from many angles, not just what they would see if they visited the cemeteries in person.

Users also must consider what their own death might be like, both from the perspective of the people who will tell their story in the future and the physical symbols that represent their lives. My narrators include a chaplain, a retired doctor, two retired nurses, a terminally ill cancer patient, and a number of older adults in their eighties and nineties. Their stories and commentary express a variety of opinions about death. My goal was not to blazon a particular ethical framework about death; rather, I hoped to provoke discussion, curiosity, and engagement with a topic that often falls in between our words. Virtually "being" with the dead might evoke all these reactions and more. Communion is a first step towards comfort, after all.

After the tradition of oral history, I sought out everyday people with direct insight into experiences of death as subject matter experts. At times, however, I break from oral history's traditional methodology and present only their current opinions and commentary, rather than exclusively using stories of their past. Although the stories and voices that I have preserved stand alone in their own right, I am examining them as a means to an end rather than an end in themselves. In this project, oral history works as a tool with which to operate upon death culture. It is important to note that these few collected histories do not form a complete picture of death in America. They are merely a few in a myriad of voices in the ongoing conversation around death. The goal that I hold that they accomplish is to contribute

to an increasingly "thick" rhetoric around death in America. Usage of "thick" in this interdisciplinary context draws from various social science connotations of "thick description," wherein contexts, explanations, and meanings pertinent to the subjects of description are an integral part of the study (Elliot). William Gavin applied this term to narratives of death in *Cuttin' the Body Loose*, but I hope it might also be applied in the future to personal accounts of end of life wishes.

The efficacy of oral history empowers both the narrator and the listener. Gavin holds that giving the dying the role of storyteller helps them to maintain their status in a community and actually overcome the social rift that can develop between a terminally ill patient and their non-terminal community context (142-143). He argues that storytelling opens up a space for the dying to step into the role of artist and teacher, both crafting an individual narrative and enriching the community's social fabric. Additionally, the existence of narratives of death from very real people contributes to the process of reifying realistic death ideas within culture. The notion of familiarization through exposure is combined here with the weighty act of listening to oral history. Simply becoming more exposed to an idea is especially important with a topic like death since our perceptions of death and dying are colored by silence, misinformation, and Hollywood performances.

Virtual reality operates in a similar experiential space, and in tandem with oral history recordings can be an extremely affective experience. VR is often touted as a productive genre for increasing empathy. Indeed, "in VR, we feel an urge to slow down, to land and really explore the moment," said Félix Lajeunesse in *The California Sunday Magazine*, "it's not just about the content itself, it's also about

creating the right conditions for the viewer to feel a part of it." Bryan Alexander

holds that "the baseline for VR storytelling" will be "grounding interacting users in

an immersive, nondisruptive setting" (181). "There at the Bridge" adheres to this

best practice. Through this method of immersive experience, I hope to invoke

empathy around experiences of death according to Jodi Halpern's characterization

in *From Detached Concern to Empathy*, "an essentially experiential understanding of

another person that involves an active, yet not necessarily voluntary, creation of an

interpretive context" (77) (italics in original). I share her sympathies with

Heidegger's "focus on shared possibilities, rather than actualities." Like the

physicians and patients in her conception of empathy, the living "may share a range

of imagined possibilities" with the dead. The experience of "There at the Bridge"

helps its audience experience a range of end-of-life viewpoints and stories, made all

the more relatable by the voices of the narrators sharing them. Through reflection, I

hope that users will discover their own lives as the interpretative context with

which to process the experience; I hope they will discover a place for their own

narrative to be written and concluded well.

In "There at the Bridge," I have combined virtual reality's features of

"immersion" and "presence." "Immersion" is "the objective quality of sensory input,

pertaining to the extent to which visual graphics, sounds... etc. feels real" (Bang and

Yildirim 292). "Presence" is defined as the "subjective experience of being in one

place or environment, even when one is physically in another" (Witmer and Singer

225). The goal of altering perceptions of reality through immersion and presence is

to help users separate from consciousness the border that divides the self and

another, opening themselves up to feel oral histories more viscerally. Heinz Kohut described this phenomenon of empathic feeling through the therapist's ability to temporarily experience herself and her patient as one being sharing a continuum of feelings (1959). Virtual reality provides a powerful platform for this kind of escapism that allows us to blur the boundaries of ourselves through disembodied experiences and more viscerally enter into the narratives of others. Philosopher F. David Martin delineates on a similar mode of experience he calls "participatory thinking." To put it simply, it involves thinking *from* something rather than thinking *at* it. Thinking *at* is necessary for critical experiences and problem solving, thinking *from* "feeds on the roots of consciousness" and sends surface self-consciousness into the background of our minds (49). It involves a kind of oneness with the object. He noted that "facing death along with participatory thinking cuts out trivialities, helps bring order out of chaos (even if only to recognize the chaos), and creates a focused purpose that generates some sense of continuity in our lives" (51-52). If celebrating story and thinking about death in virtual reality through this kind of participatory thinking can even get people to *begin* to accomplish those actions, then it will have been a great success.

The tools of virtual reality and oral history haven't had much communion in popular culture or in the academic world, and none on the subject of death and dying that I can find. What interaction they have had typically aims to create an affective experience using the visuals to document directly what the audio content is

describing.[1] Although this project is only a little more abstract than that, it's aim is not to archive and preserve in the way that most oral history programs do, nor is it merely to make oral history more engaging as an experience. Diverging from the typical mode of oral history, preservation and engagement may be wonderful tangential effects, but are not my main focus here. Rather, I hope to inspire and compel "future corpses" to consider their agency in a chapter of their story that has significant implications on not only their own lives, but those who will remember them.

Death as a Cultural Text

Death (have we stopped flinching at the word yet?) surrounds modern life. Benjamin Noys refers to the onset of the nuclear age as the moment when a background awareness of death became ubiquitous in the culture: the incessant possibility of death from above seems to color the human experience (12). We still exist in that age, however abstract or diffused the nuclear threat may be. Nonetheless, death is hardly a topic of polite conversation or a focus of society's shared spaces. Our dead are hidden away in morgues, made up to look like they're sleeping for funerals, or never seen by their survivors at all before being turned to ashes. Our dying spend their final days in hospital beds. Cemeteries sit quietly behind rural churches or are paved over and built upon (Interview with Loren Rhoads, Jarman 87). We speak of the dead in hushed tones, if at all. We certainly

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[1] See "At Low Tide: Voices of Sandy Island" by the Athenaeum Press and "Digital Oral Histories for Reconciliation [DOHR]: The Nova Scotia Home for Colored Children," a project by Kristina Llewellyn.

find it unpleasant to speak of the impending deaths of the living, or worse yet, our own. Swearing on graves has all but fallen out of vogue, but even this evolved because death carried a certain somber weight that wasn't appropriate in more everyday remarks. If our reverence was once an expression of honor, the subsequent silence has done us a great disservice: not only have we ceased symbolic exchange with the dead and dying, but we have attempted to cease the dying process, ignoring it until it is over (Noys 25). People, it would seem, "do not expect to die" (Gavin 29). Death is a cultural text that we either don't read or we gravely misread.

This misread of death translates down to the individual level. Sixty percent of Californians say that making sure family members don't have to make difficult decisions about their care is "extremely important" to them, but over half of them have not communicated these wishes. When "the conversation" was reframed to be between doctor and patient, the numbers worsen: 80% would like to talk to a doctor about end-of-life wishes, but only 7% have. The same survey found that 68% of people die in hospitals despite the fact that 70% say they would prefer to die at home (California HealthCare Foundation). What's more, the fact that 70% doctors choose not to have this kind of care for themselves brings the problem into sharp relief (Weissman, Cooper, & Hyder). In like fashion, the prevalence and brutality of CPR (great) compared to its effectiveness and side effects (poor) demonstrates just how programmed our culture is to avoid death at all costs. Death-resistance, then, while necessary in some form to humanity, has a dark side that has emerged from the modern confluence of biomedical knowledge and astounding technology. While

death and dying studies has long recognized this problem, it has not yet figured out how to rectify the fact of senescence with the innate will to live.

Our hesitance to accept or discuss death doesn't fully encapsulate America's death culture, although the idea that would shouldn't die anymore is fairly ubiquitous. Fetishization or celebration of death through gothic subcultures, dramatization of death through medical- and war-themed entertainment, and idealized death propagated by our easily digestible images of death all contribute to a kind of willful ignorance about "real" death and dying.[2] The existence of death in popular culture's curated performance and biomedicalized facade removes it from meaningful discourse: as with sex, fetishizing, idealizing, and censoring death denies its reality in lived experience. For example, television depicts CPR as having a success rate some four to ten times higher than it actually does (Diem, Lantos, and Tulsky 1996, Ehlenbach et al. 2009, Hasselqvist-Ax et al. 2015). Doctors, all too aware of this fact, confess to hiding behind medical jargon and abbreviated patient visits as ways to avoid discussing death's reality or a patient's probably trajectory through the hospital towards death (Volandes 75, 78). As it happens, sites most intimately acquainted with death are also where its reality is most vehemently denied. Jean Baudrillard posits that this process of removal has a strange, conflicting outcome: first, "little by little, the dead cease to exist" in modern society, and then death returns to society in traumatic forms (Baudrillard 126). Noys cites zombie films as one expression of this return (25), but I would add that the intensive care unit, long-term care homes for comatose patients, and the harsh realities of CPR as a

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[2] See Dina Khapaeva's *The Celebration of Death in Contemporary Culture*, University of Michigan Press 2017.

standard of care are another expression of this traumatic return. These outcomes result from a death culture that has silenced the reality of death and dying and created ignorance about end of life. The expression of that silence opens up space for death to become politicized and for power to operate upon the body through institutionalized medicine, as I will demonstrate later. For now, let's examine cultural silence and ignorance around death.

While articulating a theory of how silence operates as a rhetorical tool, Cheryl Glenn explores how not speaking can re-empower the oppressed and downtrodden. In her exploration of rhetorical silences, *choosing* to be silent grants agency to the silent because of the rebellious nature of not speaking in the specific situation. The case of silence around death and dying operates almost exactly inverse to this notion: the counter-cultural move is actually to be vocal. In death, silence is neither willful rebellion nor is it empowering. End-of-life patient advocates like Angelo Volandes, Atul Gwande, and The Conversation Project (theconversationproject.org, McCutcheon 2015) demonstrate that discussing your personal end-of-life wishes with your inner circle is the best way to ensure that care is truly patient-centered if you reach a situation in which you cannot speak for yourself. Advanced care directives fall short of enforcing wishes effectively (Castillo et al.). In fact, rather than legally enforcing your end-of-life wishes, advance directives "merely give doctors and others immunity if they follow your valid advance directive" (Commission on Law & Aging). Doctors can refuse to comply with your wishes if they have an objection of conscience or consider your wishes medically inappropriate, as long as they transfer you to another provider. While

they are necessary, they are far from the be-all end-all of end-of-life decision-making. Having a legal medical proxy who fully understands your wishes is far more effective. If you do not have a medical proxy, your family must be in unison regarding care decisions for anything to be done. During our interview, Dick Merwarth recalls how, after having palliative measures which would not prolong life explained to them,

> The family would agree and then shortly, one child would appear, and that child would usually be the one who lived across the country, who talked to their parent once or twice a year, who came to visit maybe once a year, and all the sudden, appeared on the scene, and said "No, you have to keep mother alive at all costs." And then you'd go through the whole thing over again because the other family members, who had agreed, would begin to doubt their decision.

Falling silent, as is our cultural status quo, effectively ensures that medicine and loved ones will "do everything" to save your life, including the extreme measures of all kinds that lead to increased quantity of life without improving quality (Kaufman 119, Zitter 74, Volandes 32-50). Despite mounting evidence that conversations are more useful than legal documents or ignoring the issue entirely, we tend not to have them.

Death, it seems, is active in its own removal from culture. Both in concept and execution, it obscures rhetoric. Physically, the breakdown of the body towards the end ensures that the patient, at some point, will not be able to speak. If conversations about the end of life have not been conducted before we reach the

end, we will probably not be able to have them. The silencing performed by death, however, is multifarious. We don't know what to say to the dying so we don't visit (Zitter 74); hospitals are restrictive and difficult to navigate so we can't access them with ease; we don't want to think about our parents, spouses, or children dying so we don't ask what quality of life is acceptable to them. Death both renders silence and is rendered silent. When we allow this silence before a critical care scenario arises, we empower institutions to make decisions for us, redistributing power away from the individual and helping politicize death.

Even within the hospital, death renders different silences. The American standard of offering extraordinary measures to every patient as a default is a "rhetoric of concealment," both of patient wishes and intervention efficacy (Glenn 2). We seldom realize what those interventions entail, what the physical consequences of them are, or what our chances of ever leaving the hospital are after they've been initiated.[3] Doctors are aware of these facts, but even they aren't comfortable discussing death, or they're not trained to think of death as an acceptable option (Zitter 107), and we currently find some level of nobility in being able to say that "we did everything we could." Human aversion to death runs deep.

In *Unspoken: A Rhetoric of Silence*, Cheryl Glenn recounts the tale of Pat Shipman, Associate Dean of Medicine at Johns Hopkins. After losing everything she owned in a fire, she began to suffer aphasia in the form of a loss of nouns. "It was a dual loss, first of the material manifestations of a lifetime and then of the words to describe them" (12). Psychiatrist Kurt Goldstein writes that the "lack of ability of

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[3] see Sharon Kaufman's heroic pathway in *And a Time to Die*, page 116

naming objects is often connected with a very characteristic change of the whole

personality" (301). Is it possible that a similar kind of aphasia afflicts us when we

attempt to confront the oblivion of death, which represents a drastic, final change of

the whole personality? Samuel Johnson acknowledged the confounding of

"annihilation, which is nothing, with the apprehension of it, which is dreadful" in the

18th century (Boswell 343). Kübler-Ross suggested that medical professionals

transpose their inability to speak about death into the work of preserving lives:

> Is our concentration on equipment, on blood pressure our desperate attempt
>
> to deny the impending death which is so frightening and discomforting to us
>
> that we displace all our knowledge onto machines, since they are less close to
>
> us than the suffering face of another human being which would remind us
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> once more of our lack of omnipotence, our own limits and failures, and last
>
> but not least perhaps our own mortality? (9)

It is worth considering what exactly is behind our aversion to death—and the fact

that it is shared so uniformly among so many different people, despite their level of

"expertise" on the subject.

Our cultural silence about death, or perhaps our cultural dread, is coupled

with widespread ignorance about it. I've already said that death renders silence and

is rendered silent; in a similar way, it destroys knowledge and makes itself un-

known in the one motion. In our culture, the dying have few venues to emerge as

storytellers, the living have little time to listen, and the dead have no voices at all in

a culture that has all but erased its exchanges with the dead. Robert N. Proctor and

Londa Schiebinger wrote *Agnatology: The Making and Unmaking of Ignorance* to

study how and why ignorance is created and destroyed. In this collection's panoramic survey of ignorance, it is most often a tool employed by discrete entities who stand to benefit from a specific kind of pervasive ignorance (e.g. tobacco companies' misinformation campaigns about health risks from the mid-1950s onwards (Michaels 91). In the case of ignorance about death, it is not a particular discrete entity that stands to benefit from ubiquitous death aversion, but diffuse institutions who operate as avenues for expressions of power. Although medical institutions stand to gain something fiscally, it is not their desire to harbor the dying the way that they do. Rather, a ubiquitous insistence on saving lives leads to current outcomes. They are merely actors in a larger cultural drama. For this reason, understanding root causes like the "why" and "how" of death ignorance is important.

Proctor notes that "ignorance is the product of inattention," and in a society that is deftly pushing death out of sight and out of mind, inattention is an important enemy to combat, but not the only one (7). In her essay, "On Being White," Marilyn Frye argues that "ignorance is not something simple: it is not a simple lack, absence or emptiness, and it is not a passive state…[it] is a complex result of many acts and negligences" (118). Subsequently, "because ignorance is frequently constructed and actively preserved, and is linked to issues of cognitive authority, doubt, trust, silencing, and uncertainty, it often intersects with systems of oppression" (Tuana 109). Problematically for death and dying studies, the subjects of oppression are incapacitated, voiceless, and cycle through the "system of oppression" rather quickly (in most cases). To complicate matters further, the study of death always ends in

oblivion in one way or another. Alison Wylie writes about how ontological

constraints operate upon the archaeological record in *Agnatology*. How the study of

a specific discipline is affected by the facts of the subject's identity is important in

thanatology as well. While archaeology is affected by having to look *backwards*

through time to gain understanding—wherein any number of factors might have

altered artifacts unpredictably—in death studies, we are limited by our inability to

see *forwards* beyond death. An "intrinsic condition and characteristic of the

phenomena" is the fact that we cannot ever truly know what death is like (185).

Gavin put it nicely: "Attempts to deal with death and dying are both necessary and

impossible" (191). Culture has made many attempts to rectify this issue, most

notably through the grasping-at-straws efforts of religion to definitively articulate

what comes next, but we haven't had definitive success. Despite our best efforts, we

still don't know anything for certain and we never will. Boiled down, "this means

that death itself is left excluded by death studies" (Noys 148). This ontological

constraint gives us a first exposure to an important piece of my argument about

death and dying: thanatology is mostly for the benefit of the living, only a little for

the patient, and not at all for the deceased person.

Everything that we know about the dying process, and especially what we

know about the pain involved (which is commonly cited as everyone's worst fear

about death) is limited by biomedical metrics and the decreasingly reliable and

decreasingly available information given by the dying to the living. Based on what

we know about pain, we (perhaps safely) assume that if a death was traumatic to

witness, it was traumatic to experience. This matters a great deal to the dying

subject of trauma for *a very short amount of time*. To the witnesses, the living, it matters a great deal for *an indeterminate amount of time*. In death and dying, we often get too lost in the death and forget that it is still a study grounded in living. The survivors are the ones who we can be sure must deal with the trauma and articulate the afterlife of the deceased, and this plays into how death is navigated. As one of my narrators put it when discussing a child at the bedside of their dying parent, "I think *you're* the one who needs to have the death rattle go away" (interview with Brian Cornell). Although Brian was criticizing the overuse of drugs in end-of-life situations, his underlying point rings with truth: a death is visited on the survivors many times and the dying only once, so how we experience it is significant. The processes of witnessing death, living through grief, and articulating an afterlife for the person lost are all affected deeply by the mode of death and the time spent directly in the dying process. The fact that our own deaths are only partially for ourselves can only be experienced as pain for our loved ones if we do not break from the cultural status quo and begin to erase ignorance and silence about death.

Let's return briefly to the "why" of death ignorance. Our understanding of time, avoidance of pain, and the way we form patterns of thought all play a role. Temporality gives us an initial way to put off thinking about death: "Many species (including ours) behave as if events or influences that are nearby or in the near future are more certain than those farther away or further into the future" (Smithson 213-214 in Proctor & Schiebinger). Since we as a species are notorious for our inability to experience time objectively, death and old age typically tend to

remain abstractly in the future until we are quite old.[4] If you couple this with the

view of humans as hedonic (pursuing pleasure and avoiding pain), our avoidance of

confronting death may become a little more clear (Smithson 217). Finally, and per

the bounded rationality approach first introduced by H. A. Simon, "Humans and

other animals make judgments and decisions not only under uncertainty but also

under limitations in cognitive capacity and time" (Smithson 219 in Proctor &

Schiebinger). The resulting mental shortcuts can result in a "pervasive [tendency] to

avoid information." To put this into a thanatological perspective, when we are

young, we seek pleasure without being very judicious and we feel that death is not a

very real thing, so it doesn't occupy our thoughts. Ernest Hemingway demonstrates

this through a young Nick Adams in "Indian Camp," who, after witnessing a

gruesome death, "felt quite sure that he would never die" (70). Notably, Sarah

Coombs speculates that adults are to blame for death-ignorance in childhood, since

"we might find discussing the end-of-life with those most engaged in the start of the

own to be challenging...which leads to an often elusive but nonetheless effective

sidestepping of the issue" (1). Nevertheless, from a young age we form heuristics to

help us quickly decide that it is easiest, most pragmatic, and most painless to avoid

confronting the reality of an abstract concept like death. These heuristics become

thought patterns that exist into adulthood and are partially to blame for a

widespread trend of death-avoiding individuals who also know very little about it.

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[4] "As though coming out of a dream a few years ago at eighty, I woke to find that I had long since opened this unfamiliar page in life's book called 'old age.' I must admit that I hadn't recognized much slippage before this rather late date, but it kind of makes sense considering the reputation age has among my cohorts. One doesn't brag about getting older. One doesn't even admit to it until forced to. Instead, one tries to 'think young.' I just hadn't thought much about being old. I didn't feel old; I felt good!" (Petrovski 3)

Ignorance begins to take shape. Although we remain woefully uninformed as a culture, information about dying is available if we're willing to confront our discomfort and go looking. It is important for that search to include the theater for most deaths in America today: the hospital.

Medicalized Dying

Behind the hospital's closed doors, medicine has been long waging a zealous (and usually noble) war against death. Though noble, its preoccupation with "solving death" has hindered us from experiencing a positive end of life—we usually stay alive long past the point of having quality lives because we fail to acknowledge that we are dying before death literally takes our voices. Dick Merwarth put it this way: "People begin to believe that they shouldn't die anymore." Beginning with its *modus operandi*, that "through basic biological knowledge and its clinical application, medicine can constantly advance the frontier of human health: the possibilities of progress are unlimited" (Callahan 61), we find that "death is viewed as a correctable biological deficiency that medicine has a *moral* obligation to defeat" (Gavin 62) (italics in original). In recent decades medical technology has advanced this ideal admirably. We have found a plethora of ways to put off death. The unforeseen consequences of these advancements, though, can be dire. We've blurred the lines between the living and the dead with considerable deftness. A patient with failing lungs can be kept breathing, a patient's failing heart can be kept beating, and a patient with a failing brain can be kept fed and hydrated long after they would have died without medical intervention. These prolongations evolved

because the biological fact of life (alive versus dead, binary) is given a preeminence over the various expressions of life (quality-based values, nonbinary continuum). Our experimentations with protecting human "life" have advanced so far that determining the actual moment of death can become nearly impossible or it is formally negotiated by medical procedure. Here's how Thomas Laqueur describes it in case of brain-dead patients:

> This is what happens: First, doctors use clinical criteria to rule out other reasons for someone being in a deep and persistent coma rather than whole brain death: abnormally low body temperature; evidence of barbiturate poisoning, for example. Then, they administer a battery of neurological tests, dating back to the nineteenth and early twentieth century, that cumulatively show whether the lower brain, the part that controls breathing, is functional. There are many more. All bear testimony to the glorious history of nineteenth-century neurology and, cumulatively, to the destruction of the place in the brain that controls breathing as well as so much else. Only when all of these examinations indicate that the brain stem, and hence the whole brain, is indeed dead is a person eligible for the determinative test for death. The candidate is given a big hit of pure oxygen so that her blood is fully saturated: (10 minutes pre-oxygenation). Then the ventilator is shut off. If she does not breathe within three minutes—in some jurisdictions, five or even eight minutes—she will never never never never breathe again. We know this because the part of the brain that controls breathing is, as the earlier tests had suggested, truly gone. The time of death, to repeat, is

recorded not when the patient, already suspected for some time of being

brain dead, on the basis of various neurological tests, but when she failed the

apnea test and was dead in the old- fashioned way. (148-149)

And yet, as Laqueur goes on to explain, the patient's breath is sometimes still

maintained here in order to preserve her organs for transplant. Comatose patients

become "candidates" for death, a death that becomes "real" only once a series of

tests have been passed, and "dead" patients may have warm, breathing bodies. A

wavering in the time of death has become apparent since brain death ostensibly

leads to death, but by the criteria used to define brain death, the patient must

already be dead. If we imagine this process taking place in a hospital, when does the

patient die? When brain death is officially declared behind closed doors, the patient

may be "dead," but her family may have left a "living" family member only a few

moments ago. Once they return and understand their daughter's, mother's, sister's

state, is she then dead? What then of the experience of removing life-support and

letting breath cease naturally? Peter Singer suggests that our inability to

acknowledge the brain-dead as dead is either because of our inability to relinquish

old definitions of death, or because the patients are not actually dead (34).

Medicalized dying belabors and complicates the process of dying, often in physically

and emotionally painful ways because of medicine's failure to recognize dying as

natural and acceptable, and it defaults to understanding it as an event. It also usually

fails to recognize that "death is really a process," even though individuals within the

institution see it, as retired nurse Marie Vargo-Flynn did during our interview.

Robert Morison charges us to avoid the "fallacy of misplaced concreteness" when it comes to death. He identifies the danger of squishy, process words like "living" and "dying" being replaced by apparently bounded, static words like "life" and "death" (64). These rhetorical moves can lead to death being reified as an entity, rather than a natural process; a grim reaper rather than a reverent process of altering one's modality of existence. Gavin makes a different sort of rhetorical argument, positing that "the word death does not have meaning invariance; it has meant different things to different cultures at different times. More strongly put, there is no such thing as death 'in itself,' or, if there is, we don't know anything about it" (32). As Laqueur demonstrated above, immediate physiological state is not necessarily the deciding factor in determining death; rather, only when that state is measured per the current parameters of "death" and acknowledged by relevant stakeholders can the patient be "dead." Wrote Roger Dworkin, "the law has long recognized that death occurs at different times for different purposes (e.g. property laws, homicide, tax law, inheritance, bigamy, etc)" therefore as we view death, we must view it "in context" (633). An additional context I would add is the survivors' acknowledgement. In terms of legacy and the patient's afterlife, this recognition of death may be the most important. Although institutions demand control of dying through official declarations of death and death certificates, these typically do not affect legacy and afterlife in a way that will benefit survivors. Nonetheless, in these ethically debatable end-of-life scenarios, the decision between living and dying is made by external forces, rather than the individual. Since the border between life and death has become blurry, space has opened up for power to operate on bodies

in new, profound, and often alarming ways. Due to our cultural silence about death and our widespread failure to effectively articulate our end of life wishes, the context in which we view death neglects meaning-making in a personal narrative by allowing the operation of institutions upon bodies.

Power and Death

The expression of power upon the body, once relegated to the sovereign head of state, "has become indistinct and dispersed" to sites like the hospital (Noys 54, 72). As these sites of power, with their strict protocols, standards of care, and regimented interventions, become the locations of human drama, the work of meaning-making done by stakeholders in the story is drastically affected. Increasingly, the indicator that power is operating on individuals, especially at the end of life, is their level of exposure to "bare life," first conceptualized by Giorgio Agamben (1998). Agamben is differentiating between life defined by its expression or form and life defined by its mere biological fact. As Laqueur demonstrated earlier, biomedicine has developed a formal protocol for determining the "fact of life" and placing patients in a holding pattern of bare life. Power is often observed subsuming lives by reducing their potentialities and acting on the facts of biology. In an end-of-life scenario, whether caused by senescence, terminal disease, traumatic accident, or random chance, the dying person's voice becomes muted so that "he may cry for rest, peace, and dignity, but he will get infusions, transfusions, a heart machine, or tracheostomy if necessary" (Kübler-Ross 8). The hospital becomes a site of power where "life" is preserved at the expense of the patient's voice. In bare life, the

biological fact of the individual's life takes preeminence over the quality of that expression of life and it can drastically alter how human beings exist in the world. Put differently, when expressions of life are muted, humans fail to exist meaningfully in the world, either actively failing through a medicalized dying or passively through their legacy-makers' experience of their dying. Kübler-Ross goes on: "He may wish to fight it all but it is going to be a useless fight since all this is done in the fight for his life, and if they can save his life they can consider the person afterwards." Sadly, all too often there is no medical miracle and "the person" is forever lost without a chance to speak or exert their personal agency over their deaths.

Expressions of bare life become increasingly concerning as the patient's voice becomes less intelligible; the comatose patient is the paragon of this dangerous exposure to bare life. When an individual enters a scenario when they are voiceless and their capacity to make decisions or have any sort of "meaningful life" is debatable, they are perfectly situated to become subjected to power. Their existence is defined by a state of bare life and all aspects of their identity are deferred. Because they have entered the vague threshold of death, their life lacks meaning (or perhaps the meaning is "black-boxed" by their brain-compromised state) and their death is subject to the whims of external decision-makers, utterly silencing the individual's voice. Noys draws this out nicely: "Once power isolates bare life, it then imposes on it social and legal identities" (136). These are identities that hardly anyone would elect were they given the choice, as doctors demonstrate by their refusal of medicalized deaths. By "fragmenting and fracturing" our identity

in favor of these compelled social and legal identites, Noys holds that "the bond between our existence as living beings and our existence as speaking beings" is broken. Additionally, he argues that the place of negotiating our identities is the foundation of bare life, meaning that "our exposure to death is not something that simply takes place at the moment of our death...it is the place where our identity is constituted and these identities do not offer any real means for us to resist power." By increasing the rhetoric around death and expressing our end of life wishes, we can minimize our exposure to bare life, remain "speaking beings" as long as possible, and face death on our own terms, thereby redirecting power away from the institution and through the speaking individual.

Although we may take issue with the idea that our identity is constituted by exposure to bare life, that is not an issue I take up in this paper. I do take up Noys' assertion that our identities do not offer us any real means to resist power. This attack on self-determination is important based on how "resist" is interpreted. It may be understood as either any kind of attempt to disrupt or reroute the flow of power, or an attempt to completely exit the flow of power, whether negotiated at the site of bare life or not. Of the former, I object. In creating an exposure to death and an awareness of bare life through virtual reality and oral history, I am not offering an exodus from power (which is theoretically impossible), I am attempting to diffuse power to individuals to craft their own narratives at end of life. If we buy into theories of power, then we understand it as omnipresent (Foucault 1991). If we don't, then the point is probably moot. Nonetheless, we can observe that the informed and preemptively voluble patient fares better at the end of life than she

who is ignorant, silent, and passive, going with the flow of power or anything else. (Call it a hospital intervention pathway if you prefer Kaufman's terms.) The goal in articulating what bare life is and how it may affect individuals is not to pigeonhole the debate around living and dying in the realm of theorists; rather, I hold that the contingencies of a life in which death is ignored, silenced, or misunderstood are ultimately more costly than the existential pain of facing death realistically in the present. I aim to undermine persisting heuristics of death-avoidance and the hedonistic model by demonstrating that dying is too important to be left up the whims of medicalized death.

If we are willing to broach the subject of death and discuss what kind of life is good enough for us as individuals, we can prevent a great deal of unnecessary suffering. It's important to confront these decisions long before we reach a critical care crossroads. As Martin put it, "dying time leaves little time for lucid time" (68). For him, "preparatory thinking enhanced the possibility of a peaceful letting go" when reflecting on a near-death experience. This preparation is even more important in our current medical moment: the threshold of death is wider and more vague than ever. A better articulation of end of life leads to a decreased need for a lay interpretation of terms that even medicine struggles to define and doctors struggle to talk about. This is especially important as we age because sustained survival statistically exposes us to the chance of increasing suffering at an increasing rate due to the biological facts of senescence and decay. Since medicine can now compel us to live long after life is enjoyable or meaningful, we must be intentional about dying.

Choosing death still seems, at times, ethically questionable. We certainly object if a person seems to have a great deal of life in front of them, or even a short amount of potentially meaningful life. As death becomes more immediately evident, however, we are not so wont to avoid it. My elderly narrators spoke of wishing for an "easy way to do it," avoiding a pacemaker because a heart attack "would solve my problem" (interview with Dick Merwarth), or how wonderful it would be "to go to sleep one night and wake up dead the next morning" (interview with Mickey Gerringer). Marie Flynn-Vargo noted how she would not want to be coded, a more acceptable expression of choosing death since it has been formally dovetailed with medical practice by Do Not Resuscitate orders, but no less intentional than refusing a pacemaker. These perfectly legitimate perspectives are lost when we refuse to speak about death before we are quite obviously dying. They are also a perfect example of the dying as storyteller being silenced in modern culture. In the above examples, the elderly are silenced by our inability to empathize with their paradigm, our avoidance of death rhetoric, and the very concrete walls of a retirement community that houses their stories and opinions. Ideas like this become cloistered rather than shared when we don't engage meaningfully with the "dying."

Part of this denial, especially about the legitimacy of the desire to die, can be traced to a sense of duty to protect vulnerable populations. Indeed, in *Forced Exit*, Wesley J. Smith cautions against acting on the very trend that the elders in my interview expressed—choosing death, to him, is unacceptable. Arguing forcefully against euthanasia and medical aid in dying, Smith is convinced that allowing a cultural shift that would normalize and enable a patient's death by her own will

would introduce an inescapable slippery slope wherein the elderly, depressed, and ill feel it is their duty to die or they take the "easy" way out. Unfortunately, Smith neglects to acknowledge the importance of the individual's voice both in their own identity and in the communal narrative. Smith cannot conceive of death as desirable except under "natural" circumstances, and certainly not to the dying person. He asserts that "unbridled individualism leads to social anarchy that asphyxiates true freedom" and goes on to state that self-determination is but one of several important, sometimes conflicting values (5). Conflicting values, to Smith, include "community," which relies on "mutual interpersonal care, concern and support." He does not discuss how society should negotiate conflicting values. Although I concede that his ethic of community, along with the blanket suicide prevention measures he espouses, may help protect the weak and vulnerable from premature deaths, Smith neglects to address the power that the dying hold as self-determinate storytellers to reinforce community ethics and maintain their community status. When suicide or euthanasia are unassailably condemned in culture, the very legitimate human emotions that allow for a good and desirable death are silenced or stigmatized and the people who experience them may become the very weak and vulnerable populations he wants so desperately to protect.

What's more, slippery slope arguments fall flat and betray a lack of sophistication in one's critical analysis: nuanced thinking does not call for "absolute prohibition but the contrary, great caution and specific justification at every stage" (Zaner 70). Indeed, Smith has no ability to understand approaching death from the perspective of the 98-year-old retiree. His flat denial of euthanasia's potential to

exist within a "good" end of life narrative confirms my assertion that dying is for the living, although in his case it is probably his lived discomfort with death that he is protecting through his attempts to vilify medical aid-in-dying. Wrote Mahowald, Silver, and Ratcheson, "the roadway traveled by those who make ethical decisions is unavoidably a slippery slope. To traverse it successfully requires placing wedges at the right places, in order to restrict or stop travel at those points where one is most likely to fall" (68). Smith's argument restricts the individual's ability to operate in the world by preventing them from ever even having the chance to fall, like a parent who won't remove their child's training wheels. Euthanasia, suicide, and medical aid-in-dying are perhaps an extreme expression of end of life, but our discomfort with them betrays our blundering understanding of end of life and our thoughtless exaltation of the life binary as a preeminent ideal. Whenever individuals' voices and narratives are silenced—especially about death—for any reason, space emerges for power to subsume their personal agency and ultimately expose them to undesirable ends.

Conclusion

As we look deeply into why American deaths do not match what Americans ostensibly desire for their deaths, we find a distinct gap between an idealized death and people's actions to make that death a reality. This tension exists for a number of reasons. Our feigned conception of what death is really like, caused by its tabooed nature, cultural fetishization of death images, and unnecessary mystery is in part to blame. Additionally, our culture practices a widespread ethic of silence around and

avoidance of discussing death. We prefer not to embrace the existential crisis

required of a person who confronts their mortality because we do not understand

that the road of denial is ultimately more painful. We need to begin the process of

confronting our mortality and we need to open the conversation around "real" death

again, free from as many cultural affectations as possible. Mere discussion, however,

may not be enough.

Earlier I discussed the need for "thick" description to accompany our end of

life discussions. The myriad of potential paths towards death that one might take

are overwhelming: even if someone was having robust end-of-life discussions with

their medical proxy, it would be impossible for them to articulate their specific

wishes in *every* possible contingency. As Kaufman demonstrates, there are simply

too many pathways towards death, especially once we enter the hospital to receive

care—and in the hospital, intervention decisions often need to happen quickly. The

idea behind a thick description of end-of-life wishes is that the future patient

articulates a rich enough account of what kind of life is good enough for them that

their proxy can navigate their end of life confidently. We need to tackle life's various

forms and expressions, deeply not just its facts. If a clear goal exists and we

understand that we are sacrificing "life at any cost," it becomes much easier to

decide when enough is enough. Doubt inevitably leads towards more care rather

than less.

In *Being Mortal*, Gwande puts it well: "You sit down. You make time. You're

not determining whether they want treatment X versus Y. You're trying to learn

what's most important to them under the circumstances" (113). In the same breath,

he recounts a case of successful end of life talks between a daughter and her father. The father admits that "if I'm able to eat chocolate ice cream and watch football on TV, then I'm willing to stay alive. I'm willing to go through a lot of pain if I have a shot at that." Although this is probably not the extent of their conversation, it draws an illustrative point about these kinds of conversations. Here, pain and physical functionality emerge as operational factors; comfort is something to be sacrificed with clear parameters to get to something more pleasant later. That's a good enough life. However, based on this account, if the father encountered a situation where brain capacity was the operative factor, perhaps resulting from a CPR resuscitation decision after a few minutes of oxygen deprivation, the daughter would probably *not* feel that she had enough information to confidently choose a care path for her father, should she have the option to authorize beginning code protocols or not. It is hard to say to your father, "what about if you lost some brain functionality?" But it would be a relief to know if he did not want to live that way, gave you permission to let him die, and reassured you that there is no reason to feel guilty. These kinds of moments are relegated to ambiguity and guilt about a person leaving when we do not talk richly and comfortably about death.

By articulating our feelings about death and dying with nuance, we also give meaning to life. When we value life as a biological fact above all else, we assert that every moment of life has the same level of meaning and significance because it shares the trait we apparently value most: a beating heart. When we openly express that some degrees of that life are unacceptable to us, like brain-death, a life of ventilator support, or the inability to watch football on TV, we give more meaning to

every moment of life that *is* acceptable to us. We acknowledge that these moments are temporary and we feel compelled to cherish them. After reflecting on a career at the bedside of dying patients, Marie Vargo-Flynn said, "The whole thing is, don't take the day you have for granted! Tell people you love them every day." To flip this idea into thanatological terms, our inability to engage with death as a concrete thing and necessary, even desirable eventuality for our lives equates to an inability to fully engage with life's value. Dying, after all, is for the living.

"There at the Bridge" is but one way to open up the rhetoric around death to the public and re-normalize that which was once so natural. It does not represent every kind of end-of-life scenario; rather, it merely opens the door for us to begin thinking about death in realistic, normalized ways. When Brian Cornell said, "I like to be there at the bridge," he was referring to the threshold between living and dying, but as I have repurposed the phrase, it represents a different kind of threshold. That bridge that users will cross as the experience these stories is a virtual world separates a realm of death denial and a realm of acceptance. Hopefully they will find comfort in the possibility of their loved ones sharing an idea of how they'd like their lives to end. Hopefully they will experience lightness and significance in every blessed moment that they spend vertically as long as they live. Hopefully, they will embrace the idea that dying is an integral part of living, something that adds to the richness of their life, not detracts from it.

Works Cited

Agamben, Giorgio. *Homo Sacer, Sovereign Power and Bare Life*. Stanford University

Press, 1998.

Alexander, Bryan. *The New Digital Storytelling: Creating Narratives with New Media*.

Praeger, 2017.

"At Low Tide: Voices of Sandy Island." *The Athenaeum Press*, Coastal Carolina

University, www.ccu.press/lowtide/.

Baudrillard, Jean, and Iain Hamilton Grant. *Symbolic Exchange and Death*. SAGE

Publications Ltd, 1993.

Boswell, James. *The Life of Samuel Johnson, LL.D.*Routledge, 1867.

Callahan, Daniel. *The Troubled Dream of Life Living with Mortality*. Simon & Schuster,

1993.

Castillo, Lesley S., et al. "Lost in Translation: The Unintended Consequences of

Advance Directive Law on Clinical Care." *Annals of Internal Medicine*, vol. 154, no.

2, 2011, p. 121., doi:10.7326/0003-4819-154-2-201101180-00012.

Chocano, Carina. "The Last Medium." *The California Sunday Magazine*, 5 Oct. 2014.

https://story.californiasunday.com/virtual-reality-hollywood

Coombs, Sarah. *Young People's Perspectives on End-Of-Life : Death, Culture and the

Everyday*. Palgrave, 2017.

Cornell, Brian. Personal interview. 2018.

Diem, Sj, et al. "Cardiopulmonary Resuscitation on Television: Miracles and

Misinformation." *Resuscitation*, vol. 33, no. 1, 1996, p. 96., doi:10.1016/0300-

9572(96)89069-1.

Dorman, T., and William Ehlenbach. "Epidemiologic Study of In-Hospital

    Cardiopulmonary Resuscitation in the Elderly." *Yearbook of Critical Care*

    Medicine, vol. 2010, 2010, pp. 52–56., doi:10.1016/s0734-3299(09)79215-9.

Dworkin, Roger. "Death in Context." *Indiana Law Journal*, no. 48, 1973.

Elliot, Mark, et al. "Thick Description." *Oxford Reference*, 1 Jan. 2016,

    www.oxfordreference.com.libproxy.lib.unc.edu/view/10.1093/acref/978019181

    6826.001.0001/acref-9780191816826-e-0410.

"Final Chapter: Californian's Attitudes and Experiences with Death and Dying."

    California HealthCare Foundation.

https://www.chcf.org/wp-content/uploads/2017/12/PDF-

    FinalChapterDeathDying.pdf

Foucault, Michel. *Discipline and Punish the Birth of the Prison*. Penguin, 1991.

Frye, Marilyn. *The Politics of Reality: Essays in Feminist Theory*. The Crossing Press,

    1983.

Gavin, William Joseph. *Cuttin the Body Loose: Historical, Biological, Personal*

    Approaches to Death and Dying. Temple Univ. Press, 1995.

Glenn, Cheryl. *Unspoken: a Rhetoric of Silence*. Southern Illinois University Press,

    2004.

Goldstein, Kurt. "The Problem of the Meaning of Words Based upon Observation of

    Aphasic Patients." *Journal of Psychology*, 1936, pp. 301–316., doi:10.1007/978-

    94-010-2855-4_9.

Halpern, Jodi. *From Detached Concern to Empathy: Humanizing Medical Practice*.

    Oxford University Press, 2011.

Hasselqvist-Ax, Ingela, et al. "Early Cardiopulmonary Resuscitation in Out-of-

    Hospital Cardiac Arrest." *New England Journal of Medicine*, vol. 372, no. 24, 2015,

    pp. 2307–2315., doi:10.1056/nejmoa1405796.

Hemingway, Ernest. *The Complete Short Stories of Ernest Hemingway The Finca Vigia*

    Edition. Paw Prints, 2011.

Kaufman, Sharon R. *... And a Time to Die: How American Hospitals Shape the End of*

    Life. University of Chicago Press, 2006.

Khapaeva, Dina. *The Celebration of Death in Contemporary Culture*. University of

    Michigan Press, 2017.

Kohut, Heinz, et al. *Introspektion, Empathie Und Psychoanalyse Texte Aus Den Jahren*

    1959 Bis 1970. Psychosozial-Verlag, 1959.

Kübler-Ross Elisabeth, and Ira Byock. *On Death & Dying: What the Dying Have to*

    Teach Doctors, Nurses, Clergy & Their Own Families. Scribner, a Division of Simon

    & Schuster, Inc., 2014.

Llewellyn, Kristina. "Digital Oral Histories for Reconciliation (DOHR): The Nova

    Scotia Home for Colored Children." *University of Waterloo*,

    uwaterloo.ca/renison/dohr-media-coverage.

Mahowald, Mary B., et al. "The Ethical Options in Transplanting Fetal Tissue." *The*

    Hastings Center Report, vol. 17, no. 1, 1987, p. 9., doi:10.2307/3562434.

McCutcheon Adams K, Kabcenell A, Little K, Sokol-Hessner L. "Conversation Ready":

    A Framework for Improving End-of-Life Care. IHI White Paper. Cambridge,

    Massachusetts: Institute for Healthcare Improvement; 2015. (Available at ihi.org)

Merwarth, Dick. Personal interview. 2018.

Michaels, David. "Manufactured Uncertainty: Contested Science and the Protection

of the Public's Health and Environment." Agnatology: The Making & Unmaking of

Ignorance, Stanford University Press, 2008, pp. 90–107.

Morison, Robert S. "Death: Process or Event?" *Death Inside Out*, Harper Forum

Books, 1975.

"Myths and Facts About Health Care Advance Directives." American Bar Association

Commission on Law & Aging.

https://www.americanbar.org/content/dam/aba/migrated/Commissions/myths_fa

ct_hc_ad.authcheckdam.pdf

Noys, Benjamin. *The Culture of Death*. Berg, 2005.

Petrovski, Sue Matthews. *Shelved: a Memoir of Aging in America*. Purdue University

Press, 2018.

Proctor, Robert, and Londa L. Schiebinger. *Agnotology: the Making and Unmaking of

Ignorance*. Stanford University Press, 2008.

Rhoads, Loren, and Casey Jarman. "Loren Rhoads." *Death: An Oral History*, Pulp,

2016.

Simon, Herbert Alexander. *Models of Bounded Rationality*. MIT, 1997.

Singer, Peter. *Rethinking Life & Death*. Oxford University Press, 1995.

Smith, Wesley J. *Forced Exit: Euthanasia, Assisted Suicide and the New Duty to Die*.

NATIONAL Book NETWORK, 2006.

Smithson, Michael J. "Social Theories of Ignorance." Agnatology: The Making &

Unmaking of Ignorance, Stanford University Press, 2008, pp. 209–229.

"The Conversation Project." *The Conversation Project*, theconversationproject.org/.

Tuana, Nancy. "Coming to Understand: Orgasm and the Epistemology of Ignorance."

Agnatology: The Making & Unmaking of Ignorance, Stanford University Press,

2008, pp. 109–145.

Vargo-Flynn, Marie. Personal interview. 2018.

Volandes, Angelo E. *The Conversation: a Revolutionary Plan for End-of-Life Care*.

Bloomsbury, 2016.

Weissman, Joel S., et al. "End-of-Life Care Intensity for Physicians, Lawyers, and the

General Population." *Jama*, vol. 315, no. 3, 2016, p. 303.,

doi:10.1001/jama.2015.17408.

Witmer, Bob G., and Michael J. Singer. "Measuring Presence in Virtual Environments:

A Presence Questionnaire." *Presence: Teleoperators and Virtual Environments*, vol.

7, no. 3, 1998, pp. 225–240., doi:10.1162/105474698565686.

Zaner, R. M. "Anencephalics as Organ Donors." *Journal of Medicine and Philosophy*,

vol. 14, no. 1, 1989, pp. 61–78., doi:10.1093/jmp/14.1.61.