

CONFRONTING THE UNAVOIDABLE

Death is unavoidable, yet we still try to avoid it and call it by any other name. Tiptoeing around the topic, we tuck it away in our compartmentalized mental boxes with the label “to deal with later”. But why is later any better than now? Are we assuming we will become more capable at a specific point in the future, more prepared for death by ignoring it longer?

I know the delusion well; I spent years mentally stacking other boxes on top of and around my “to deal with later” box. The box will only grow and, at a certain point, you can no longer hide it, no longer push it behind the other boxes. It refuses to remain unopened. And even though we sometimes pretend otherwise, death is natural. Nearly 150,000 people die worldwide each day (Krieger), but “over the last 150 years American death care has positioned human death outside of the cycles of nature” (Kelly 38).

For the purposes of this final project, since I partnered in the research phase with Hospice of Wake County, it makes little sense to discuss the societal implications of dying, death and grief in other societies besides my own. The culture of death, from this point on, will be discussed in relation to the United States societal experience. Both the past and current culture of death in the United States has been described as “one that denies and fears death” (Wasserman 621). But death is natural, death is difficult and death is important.

Death Is Natural

I have yet to come across a more concise and poignant explanation of death than in the following: Death is a process —“sometimes protracted, and often painful to experience, witness, and accept” (Astrow and Popp 1885). Death is the final process of life, a product of living.

Easily embracing the concept of birth and celebrations of life along the way—birthdays, graduations, marriages, more births—why do we pretend death is not the natural (and logical) conclusion of life as we know it? Perhaps we are too afraid, too concerned, or fearful? Instead we choose to keep death at a distance, dead bodies at a distance, and especially dying bodies at a distance (Kelly 38-39).

We Deny Death

There is a trickle down from the healthcare industry in regards to the way we deal with death as a society. Over the course of the last few decades, we have attempted to quarantine death and confine its occurrence to hospitals and nursing homes. At least a third of Americans die in hospitals, and the dead bodies are then sent down to basement morgues and from there carted to funeral homes (Kelly 38-39). Death has been restricted to occur in solitude, instead of within the community, and our discomfort with death has only increased as a result.

Without being able to witness death, we do not know how to die (Gillis 112). Culturally, we are not even comfortable with uttering the accurate words *she died* or *he died*; instead, we opt for phrases like “passed on,” “at rest,” and “no longer with us” (Wasserman 621). There is a history of our society denying death and the dying, and there is precedence to witness an increase

in our denial. Even aging is culturally terrifying: a peek inside nearly any magazine or cosmetics aisle will provide verification (Johnson and McGee 719).

To confront death in others would mean to confront death for ourselves and knowing the dying would elicit a response from the living; their pain would resonate (Bloom 78).

We Underestimate Death

Again, the trickle down from the healthcare industry comes into play here—doctors underestimate death and underestimate patients' abilities to deal with a prognosis of death. Studies do find that, in most cases, when cancer is not curable, the doctors will inform the patient of that fact but withhold information regarding prognosis (Gawande). Patients end up with warped views of their own chances of survival. In a study led by a Harvard researcher asking doctors of nearly 500 terminally ill patients to estimate their prognosis, “sixty-three percent of doctors overestimated survival time. Just seventeen percent underestimated it. The average estimate was five hundred and thirty percent too high. And, the better the doctors knew their patients, the more likely they were to err” (Gawande).

We Changed Death

Maybe doctors have simply not had enough time to acclimate to the way death has changed. The way Americans die has morphed into something unrecognizable in the last 200 years (Carr 184). In the 19th and early 20th centuries, dying was usually a brief process and the result of infection, difficulty in childbirth, pneumonia or heart attack (Gawande). Dying had accompanying rituals, as did death: *ars moriendi* (the art of dying) guides were ubiquitous and consoled families with their pages of prayers and questions for the dying (Gawande). Fast forward to where our culture of death exists now: death typically comes at the end of a battle with an incurable disease. What remains is the certainty of death. What has changed is the timing (Gawande).

“Technology sustains our organs until we are well past the point of awareness and coherence. Besides, how do you attend to the thoughts and concerns of the dying when medicine has made it almost impossible to be sure who the dying even are?” (Gawande). For most Americans, especially older Americans, an accurate conceptualization of the end of life means understanding it as a process—as dying—and not as an event—death (Carr 184).

Death Is Difficult

“Then I realized, death is a normal part of life. It may never get easier to deal with, but each time it happens to someone we know, each exposure can be an inoculation against the fear, and we can become stronger in the presence of it” (Williams). But few of us actually see death, witness dying. We hide death in hospitals and nursing homes behind closed doors.

What about the dying? Do they wish to be quarantined? Are we afraid death is contagious? This past winter, I was visiting my ninety-six year old friend, Dorothy, who had just been transferred to a single room in her nursing home facility because she was *transitioning*, end-of-life care lingo for *dying*. I was with Dorothy for an hour that day, quietly reassuring her that I was still in the room, that she was not alone, counting the audible seconds between her breaths with the persistent tick of the wall clock.

Thinking she was going to die on my watch, the emotion that stirred within me was a confusing mix of fear, relief, and nervousness. Fear: I have only known Dorothy for a single year, and I did not want to be the one who was there when her body stopped living. I wanted her family members there. Relief: how tired a body must be after ninety-six years of living, especially a body ravaged by disease, sickness and frailty. Nervousness at the logistics of being present at a death; this would be my second in two years, and I had already forgotten the signs. And there are signs. There are always warnings that death is impending. I felt her hands—freezing. After more than forty visits with my friend, that was the first time she did not squeeze my hands back.

And then the memories roll in, one after the other: Two years ago, it was my mother in the bed, a hospital bed not in the hospital but in her room, our makeshift control center, where we kept her medicine, her adult diapers, bed pads, extra sheets. We slept in shifts on the futon next to her bed, waking up every two or three hours to check on her during the night. The hours passed more slowly during the days and on that very last day, when I held her thin, cold hands, she stopped squeezing back.

Grief Is Complex

Grief is a result of confronting death and dealing with death. Regarding grief, Meghan O'Rourke writes in her first entry of "The Long Goodbye" series: "A piece of you recognizes it is an extreme state, an altered state, yet a large part of you is entirely subject to its demands." Grief is an extreme state, albeit a necessary state surrounding loss. It is difficult to confront though—in the same entry O'Rourke writes that we are only willing to confront the loss in the form of self-help and under the guise of healing our grief. We have even latched onto the idea of grieving in stages: why? Maybe because it allows us to believe loss is controllable, something we desperately want to be true (O'Rourke, "Good Grief").

Our Grieving Is Inadequate

The truth is that no type of grief follows a checklist, a pattern or any order. Grief is messy, complicated, and non-linear. Elisabeth Kubler-Ross, the woman who popularized the five stages of grief model, even insisted later in her life that the stages she presented were not meant to make the emotions of grief neat and organized (O'Rourke, "Good Grief"). A more honest understanding of grief is that it comes in incoherent, irrational waves. (O'Rourke, "The Long Goodbye: Entry 3").

Death Is Important

A better understanding of death should lead to a better understanding of grief. Why are we unwilling to understand death more closely? Why do we deny its importance? There is a subtle shift in our culture's treatment of death, but it's been slow—since 1967, the death awareness movement has maintained a quiet presence, but it is not enough (Mak and Clinton 97).

Our System Is Falling

Certainly the whisper of the death awareness movement cannot out voice the roar of our medical technology moving ever forward.

When there is no way of knowing exactly how long our skeins will run—and when we imagine ourselves to have much more time than we do—our every impulse is to fight, to die with chemo in our veins or a tube in our throats or fresh sutures in our flesh. The fact that we may be shortening or worsening the time we have

left hardly seems to register. We imagine that we can wait until the doctors tell us that there is nothing more they can do. But rarely is there *nothing* more that doctors can do. They can give toxic drugs of unknown efficacy, operate to try to remove part of the tumor, put in a feeding tube if a person can't eat: there's always something. We want these choices. We don't want anyone—certainly not bureaucrats or the marketplace—to limit them. But that doesn't mean we are eager to make the choices ourselves. Instead, most often, we make no choice at all. We fall back on the default, and the default is: Do Something. Is there any way out of this? (Gawande)

By putting off preparation for end-of-life, we arrive at death unprepared, and as a result, our deaths are not good deaths. A national project, *Coping with Cancer*, published a study four years ago that demonstrated a strong correlation between declining quality of life and increasing last-ditch medical interventions—electrical defibrillation, chest compressions, being put on ventilators. Six months post-death, the caregivers of the deceased patients were more likely (three times more likely) to suffer from major depression.

Spending one's final days in an I.C.U. because of terminal illness is for most people a kind of failure. You lie on a ventilator, your every organ shutting down, your mind teetering on delirium and permanently beyond realizing that you will never leave this borrowed, fluorescent place. The end comes with no chance for you to have said goodbye or "It's O.K." or 'I'm sorry' or 'I love you.' (Gawande)

Once the practice of medicine became oriented towards interventions for postponing death and more directed at treating diseases, we stopped treating the patient (Kuczewski 411). And somewhere along the way, we forgot that quality of life and quantity of life are not synonymous and that the terminally-ill patient is the only person qualified to make decisions about his or her quality of life (Welsh).

A person dies only one time, and comes to death with no exact understanding of what will or will not happen. It is the responsibility of the medical community to help patients facing the end of their lives to prepare for the decisions they will face (Gawande). "Our medical system is excellent at trying to stave off death with eight-thousand-dollar-a-month chemotherapy, three-thousand-dollar-a-day intensive care, five-thousand-dollar-an-hour surgery. But, ultimately, death comes, and no one is good at knowing when to stop" (Gawande).

Remedying the System

In standard medical care, treatment is aimed at postponing death and therefore prolonging life, without regard for quality of life. In hospice care, treatment is aimed at acknowledging death, and maintaining quality of life (Gawande). Hospice, as a philosophy, has attempted to bring death back into the conversation about life. Hospice, as a practice, has begun to bring death out of the hospital and back into the home. "Probably the best social resource we have for reducing denial of death is the hospice movement" (Johnson and McGee721).

Hospice is about patient oriented care, focusing on reducing or eliminating pain and discomfort—physical, mental, psychosocial, and emotional pain. The top priorities of terminally-ill patients are avoiding suffering, spending time with family, physical touch, mental awareness, and avoiding being a burden. While our standard medical care mostly fails to acknowledge these concerns, they are a priority for hospice care (Gawande). "Hospice has tried to offer a new ideal for how we die. Although

not everyone has embraced its rituals, those who have are helping to negotiate an *ars moriendi* for our age. But doing so represents a struggle—not only against suffering but also against the seemingly unstoppable momentum of medical treatment” (Gawande).

Marking Dying

Death is certainly an unknown, but dying could be more familiar if we allowed it. Perhaps death could be met with less confusion and less fear if we understood what it meant to confront dying. If we allowed the dying back into the space of the living, as a society we could make more sense of death and dying, grief and grieving. We could inch closer to a collective catharsis (Bloom).

Dying As a Disaster

“If I told the story of her death, I might understand it better, make sense of it—perhaps even change it. What had happened still seemed implausible. A person was present your entire life, and then one day she disappeared and never came back. It resisted belief” (O'Rourke, “Story's End”). I think death will always resist belief; it is our human nature to find that magnitude of personal loss beyond comprehension. Regardless, death persists, and becomes disastrous to our lives. Death is a disaster, an event which shatters “the continuities of our experiences and breaks the moral sense through which we understand and order our lives” (Awalt 5).

Those facing death face the disaster, and those that survive the death, survive the disaster. Through the disaster of death, we suffer. “Suffering defies language and evades all attempts at expression” (Fisher 65). Yet we must still try to express it, even though what we come up with “will always be fragmentary and incomplete. In no way can we totally name or inscribe the disaster. When all has been said, it still stands unexhausted and inexhaustible” (Awalt 5).

The attempt at expressing the disaster of death and dying does not mend our reality and does not heal our hurts, but keeps us aware of the wound. Acknowledgement breeds awareness which breeds discovery (Awalt 16). Meaning cannot be found in death and dying without acknowledging the wound of its disaster.

Dying as Understanding

And if we view dying as a fundamental part of life, then dying would not occur in isolation, but rather as an interpersonal experience, just as the rest of life is (Fisher 71). We must allow our identities to be affected by the presence of death, of dying and of suffering (Fisher 3). Familiarity with death—studying death and the dying—can improve our awareness and understanding of the concept of a *good death* (Wasserman 621). With regards to the dying, those facing terminal diagnoses, “we must recognize their personhood, their right to say goodbye when they are ready. We must allow people to die; we must say to them, and tell them, 'it is alright to die.' We must let go” (Fisher 72).

If our collective consciousness is shifted enough, perhaps we will start using dying as a learning experience, a way of understanding how to prepare for our own turn to face death.

Dying As an Investigation

One method of acknowledging the wounds of death and dying and beginning to shift awareness is through investigation—probing our way into the pain. Art can offer assistance here, as art is meant to investigate, to reveal what our society resists acknowledging (Bloom 79).

“Over the years, many questions have arisen about the connection between creativity and madness, the artist and the madman. There is a connection, but not necessarily because you must be crazy to create. Both the artist and the madman speak a tongue that has become foreign to the rest of us. The mad person is to his or her family what the artist is to the culture, containing what is hidden, secret, denied, and dissociated and trying with more or less desperation to reveal the vital secrets to us all.” (Bloom 79)

Artists try to illuminate what we, as a society, keep hidden and to bring to light what we need to know, have perhaps simply forgotten, or fear far too much to know (Bloom 79-80). The arts have the ability to transform and deepen how we perceive and understand death and dying (Aulino 493). “The artist has a responsibility to help society deal with its hidden conflicts and contradictions and must embody hope in any way possible. To do this we must be able to share in a vision of what does not, but still could, exist” (Bloom 80).