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Kayla Stock
kayla.stock@outlook.com

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Life or Death and Other False Dichotomies:
A Theology of Hospice

Kayla Stock
Master of Divinity Candidate
Saint John’s University School of Theology and Seminary
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Say not in grief that she is no more
but say in thankfulness that she was.
A death is not the extinguishing of a light,
but the putting out of the lamp
because the dawn has come.¹

You were the beloved before you were born,
and you will be the beloved after you die.
That’s the truth of your identity…
You belong to God from eternity to eternity.
Life is just an interruption of eternity,
just a little opportunity for a few years to say,
‘I love you, too.’²

In 2002, when I was eleven years old, I felt the weight of my own mortality for the
first time. As a sixth grader, I was of course old enough to understand that no one lives
forever. People die. I had attended a small handful of wakes and funerals including my great-
grandmother’s funeral approximately five years earlier. I had not, at that time, experienced
the loss of someone whom I knew well. At this time, I was not unaware of the fact that I too
would someday die. However, this was the first day I truly held the weight of my own
mortality. I felt it deep in my bones—and it terrified me.

Considering the immensity of the inevitable death and decay that marks human
existence, this realization came to me in a rather benign, seemingly harmless way via the
lowly mosquito. At eleven years old, this was the first time that I had heard of the potentially
lethal West Nile virus, which is transmitted by mosquitoes. My mind spiraled into memories

¹ Rabindranath Tagore, (memorial service homily, Lutheran School of Theology, Chicago, IL, March
29, 2006) as quoted in Rev. Dr. Vitor Westhelle, “…Because the Dawn has Come,” in Mission with the
Marginalized: Life and Witness of Rev. Dr. Prasanna K. Samuel, ed. Samuel Meshack (Tiruvalla: Christava Sahitya
² Henri Nouwen, (U.S. National Catholic AIDS Network, July 1995) as quoted in Michelle O’Rourke,
of Minnesota summers and the multitudes of mosquito bites I had ever received to that point, projecting forward into the seemingly innumerable amount more I would yet receive in the rest of my life. Death by mosquito seemed to me to be my inevitable demise; it would surely mark the end of my tale. Was I already living out my swan song? My life was just beginning, and how soon, it seemed, it was to be taken away from me.

Now, at this point, I am happy to report that I have successfully outlived each and every mosquito with whom I have ever crossed paths, which makes this brief flashback a somewhat sad, mostly amusing vignette. However, the anxiety that I experienced at that time was absolutely real. The anxiety around the idea of death resulted in many sleepless nights, eventually morphing into a long-lasting depression, which threatened my life much more so than any insect ever did.

Anxiety and fear of death are completely natural. They also can be dangerous. However, all hope is not lost. It is my prerogative to demonstrate that when faced head-on, processing one’s inherent death anxiety can lead to human flourishing. One has a choice when faced with an anxiety-producing stimulus. Choosing to learn about rather than run from my own death anxiety, death and dying as well as grief and loss have become personal and professional passions of mine. This has led to my current work in the field of hospice nursing. I seek to integrate my understanding of the health care environment with my knowledge of pastoral theology, systematic theology, and spirituality. In doing so, I endeavor to be able to speak to both medical and theological communities.
There are many ways in which negative images and conceptions inform our understandings of death. It is human nature to have an underlying anxiety toward death. Evolution necessitates it. However, our high executive functioning is able to lead us astray in this way. Death is the ultimate unknown, which is understandably problematic for a species superb in its executive functioning and reasoning. Further, there are many specific systems that perpetuate a negative understanding of death. Medicine and health care are arguably among the biggest culprits. I will investigate further into the ways that medical mechanizations teach health care providers and therefore general society that death is failure. It is clear that science alone cannot answer the question of the meaning of human mortality, human limitedness, human finitude. Science alone cannot answer the fundamental question, ‘what is it that makes us human?’ Science is essential but ultimately insufficient in answering this question. Thus, I turn to theology, specifically theological anthropology and Christology to further address the question, hoping to find compelling images and understandings of death that may expand the conversation from death’s connection to anxiety-ridden darkness. I will attempt to construct a theology of hospice from this foundation to demonstrate how accepting one’s limitedness, one’s inevitable and eventual death, can be a sure way forward into an enriched life, a life of human flourishing. Much about the way we are taught to think about and imagine death sets us up for failure. By shifting paradigms and reimagining death not as the opposite of life, not as life’s antithesis, we may temper the anxiety of death and learn to appreciate life in the present moment.

Before progressing further, I would like to claim the ground from which I stand and from which I write. I am a baccalaureate prepared registered nurse. I have been working in
various fields within health care as a nurse for approximately five years, and I have most recently begun working in home-based hospice care. There have been many people in my life that I have been close to that have died from such causes as various forms of cancer, old age, or suicide. None of these deaths were from interpersonal violence in the form of physical, emotional, or domestic abuse. None from warfare. As such, I recognize and would like to name the point of privilege from which I write. I believe that one’s own mortality is a topic that all people will face eventually assuming they live long enough lives and have the cognitive capacity to be able to engage with these ideas. However, the perspective of my own privilege, which I am wishing to name, is that the idea of my own death is not something I naturally encounter on a daily basis. Barring unforeseen tragedy whether accidental or biological, my life expectancy, statistically, is quite high. For many people in the world today, life is survival; they must daily face the reality that tomorrow is not ensured—due to poverty, war, ecological degradation, or one of many other causes out of their control. Thus, I would like to recognize that what some people have no choice but to face each day, others are able to choose to engage with from a theoretical perspective, and I believe there is significant privilege in this.

Further, the words of this paper are not intended to soothe aching and mourning hearts. I do not foresee significant bedside application of these ideas. A strong therapeutic relationship and skilled pastoral care capabilities would be necessary to do this well. Rather, my hope is akin to Henri Nouwen, who writes

It seems indeed important that we face death before we are in any real danger of dying and reflect on our own mortality before all our conscious and unconscious energy is directed to the struggle to survive. It is important to be prepared for death,
very important; but if we start thinking about it only when we are terminally ill, our reflections will not give us the support we need.

In doing so, may we never forget those people for whom these questions are a daily, unchosen reality.

I. Why Does Fear Come So Naturally?

Fear and Anxiety

In much of the literature on the topic, the terms death anxiety and fear of death seem to be used interchangeably. However, when considered apart from the topic of death, anxiety and fear are far from synonymous terms. The Corsini Encyclopedia of Psychology defines anxiety as, “a future-oriented emotional state characterized by a sense of apprehension, worry, and lack of control of one's own affective response.” Further, “Anxiety should be differentiated from fear, a distinct and basic emotion that is best conceptualized as a primitive alarm in response to present danger. In contrast, anxiety is concerned with future threat.” Conversely, the experience and emotion of fear is defined as “the immediate subjective experience of apprehension marked by activation of the fight or flight response.” Additionally, “the great majority of phobias are about objects of natural importance to the survival of the species.” The survival of one’s species is ensured through the successful transmission of genes into future generations. That which is interpreted as

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3 Henri Nouwen, A Letter of Consolation, as quoted in Ibid., 42.
6 Ibid.
harming one’s ability to procreate thereby has the potential to risk the survival of the species, albeit in a micro-level way. Therefore, the emotion of fear has been evolutionarily adaptive in that it protects an organism against real or perceived harm that is deemed to have the potential to inhibit one’s ability to survive. The emotion of fear is intended to be a short-lasting experience, lasting just long enough to either fight, flee from, or freeze in the midst of the fear-inducing object. Fear “is a normal emotion exhibited in potentially dangerous situations” specifically “when danger is physically present.”9 It is clear that evolutionarily fear is based on present, in some way tangible objects. It is the fear of the act of dying that prompts fighting, fleeing, or freezing.

However, what happens when the fearful stimulus is death itself rather than the act of dying? This is what sets humans apart from all other creatures. Other organisms are aware of their mortality in the sense that they are motivated to stay alive, to continue living. Humans alone are able to contemplate their own mortality; only humans are capable of fearing death itself, rather than being instinctually inclined to continue living by avoiding dying. “The brain, with its primitive and rational fear systems, tries to use past events to predict an inherently uncertain future. Since the future may bring disaster, it is always the object of at least a low level of fear. This is fundamentally a fear of the unknown and originates in the extraordinary ability our frontal lobe gives us to analyze and plan for the future.”10 Death is fits the criteria as a fear-inducing object since life itself is—of course—an object of “great

importance to the survival of the species.” However, as most commonly experienced in everyday life for the majority of our lives, death lacks a sense of immediacy. Fear of death necessitates a future-orientation, a future that is fundamentally unknowable. Fear of the unknown is fundamentally what causes death anxiety.

What are we to do with fear of the unknown when the unknown is fully unknowable? Psychotherapist Yvonne Agazarian has created a psychotherapeutic model that names sources of anxiety. She identifies that “the source of anxiety is attributed to one of three causes: 1.) anxiety-provoking thoughts, 2.) physiological experience of emotion, 3.) normal excitation at the edge of the unknown.” As described previously, death is the ultimate unknown. As such, Agazarian’s theory of the anxiety of the edge of the unknown is most applicable within this context. She defines the edge of the unknown as “the apprehensive experience of being in uncertainty, often mixed with dread and anxiety about not knowing what is going to happen next. When curiosity about the unknown is aroused, energy is revectored and the experience transformed from dread and/or anxiety into excitement, anticipation and wonder, which is labelled as apprehension at the ‘edge’ of the unknown.” In order to stay present to one’s current experience, Agazarian instructs the therapist to help the individual name that what is unknown to them is in fact unknowable at this time; therefore, since the worrisome thought cannot and need not be fixed or figured out, the therapist helps the individual to become curious or even excited about the undisclosed

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11 Seligman, "Phobias and Preparedness - Republished Article," 582.
13 Ibid., 299.
14 Ibid., 302.
potentials of the unknown event. Becoming curious rather than anxious about the unknown event or object allows a person to integrate this unknown quantity into their larger understanding of themselves and their current situation.

For instance, a person may be worried about if they will be able to succeed in a new position at work. Since their future performance is fundamentally unknowable to them at this time, to stay in the position of anxiety is non-productive and could even be detrimental. Instead, they can name that worrying about a future event is fruitless, while instead becoming curious. Then, they may realize that they are feeling unsure about their level of knowledge of a given subject, then channeling their energy into learning more before they begin the new line of work.

Fear of Death in the Context of Liminality and Limitedness

Human beings are creatures of habit, creatures that thrive in control and certainty. As the saying often attributed to Benjamin Franklin goes the only things certain in life are “death and taxes.” In a sense, death therefore is the most knowable thing; the only thing every single person can be assured that they will experience. There is no way by it, only through it. Death “is one of the few universal givens (together with birth) that applies to every person on the planet, and inextricably links us to our animal cousins in that we cannot truly control or avoid it.”15 Therefore, death is simultaneously both the most and the least knowable human event. This seeming contradiction is at the heart of the mystery of what it means to be human. “We are repelled and fascinated by death and the profound mystery that

it represents.”

People will go many lengths to avoid this tenuous liminal and limited space. Humans experience death anxiety as a liminal space in that we are never as fully and safely out of view of death as we may hope to be. “The greatest unknown is death itself. For that reason, and the pain often inherent in the process, fear of death becomes in most people the primary fear.” We know that it is coming, but rarely do we know the time or nature with which it will arrive.

Human limitedness causes tension and can contribute to death anxiety. Facing and coming to terms with one’s eventual death by nature involves facing one’s mortality, one’s humanness. It means that one day in the near or distant future we will be forced to release our grasp on the only existence we can remember. Belief systems have been built around what happens next, what exists beyond. These have the ability to offer hope and comfort or fear and foreboding. Even so, this does not diminish the fact that our lives are more fragile and impermanent than we might hope.

One benefit in the face of our liminality and limitedness is that humans are meaning-making creatures. Vahrmeyer and Cassar describe that the participants in their study of death anxiety were “unanimous in the view that it is necessary to create meaning in life, and that this meaning in turn serves to veil some of the terror of the unknown.” Vahrmeyer and Cassar discuss the work of Ernest Becker stating that “Becker hypothesized that death anxiety is our primary ontological condition, causing us to find ways to deny our mortality,

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17 Ibid., 129.
through means which are embedded in our culture, religion, and society, which he termed immortality projects.”

Vahrmeyer and Cassar describe two main types of immortality projects: “those featuring a death transcending component, or those enabling the participants to cope with their ontological condition in other ways” both of which seem to be “universally employed.”

It is possible to allay fear of the unknown through the appreciation of the inherent liminality of our lives by being present to ourselves and those around us in the immediate moment. Immortality projects inspire hope in that they allow people to “feel they are creating or joining something which will last forever. People then become heroic—part of something eternal, something that, unlike the physical body, will never die.”

Wong and Tomer concur, stating “the heart and soul of overcoming death anxiety and living an authentic happy life lies in the human capacity for meaning making and meaning reconstruction…More specifically, it is the life-enhancing and life-expanding quest for meaning that enables us to live fully in the light of death.”

In participating in meaning making around human mortality, human flourishing is possible.

However, all of this happens at a micro-scale. The fear of death that individuals experience occurs out of evolutionary, biological necessity. However, there are many systems that reinforce this same understanding of death, in particular the health care system in the Western world.

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19 Ibid., 151.
20 Ibid., 155.
21 Ibid., 151.
II. The Shortcomings and Successes of Medicine

While death anxiety and death denial can be seen as evolutionary instincts or adaptations lying at least partially outside the realm of human control, there are also external cultural mechanisms and systems that contribute negatively to the view of death. The health care environment is one such location. Medicine exists in this negatively judged orientation toward death for two main reasons: an underappreciation for what it is that makes us human and an overreliance on technology.

The Human Experience of the Medical Monster

Much of the health care provided in hospital settings fits within the biomedical model of care, in which the hospital exists as “a place that one comes to as a stranger in need of care, and a place that one visits temporarily.” This care model is “fundamentally solution-oriented. There is a problem, such as illness or pain, and for every problem there is both a cause and a solution.” This clearly structures a hierarchy and imbalance of information with doctors and providers becoming the bearers of information. Callahan concurs regarding this model of health care, which:

looks to reductionist and analytical science to provide the ultimate answer to human disease. The reigning model of the body is that of a complex machine, and the task of the doctor is to correct its breakdowns and defects...The aim is a full and comprehensive understanding of disease reduced finally to its core and causal elements.25

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23 Tara Flanagan Tracy, "Hospice Care and a Theology for Patients at the End of Life," Dialog 53, no. 3 (2014): 260.
24 Ibid.
Further, “though sometimes maligned as maintaining a mechanistic and reductionist view of the human person, ultimately, the goal of the biomedical model is health and long life, one free from preventable disease and needless physical suffering.”

Clearly, the values and goals underlying the biomedical model of health care are commendable ones. Preventing disease and physical suffering are morally and ethically appropriate goals. Further, there are many instances in which this model of care works fairly well, especially in first-world countries.

With the ever-expanding understanding of the human body, more diseases that were once swift death sentences are now considered to be either chronic diseases that can be relatively easily managed or else they are cured and eradicated all together. Yet, there is much about the human condition that the biomedical model leaves behind.

Certainly in the United States, a diagnosis of HIV/AIDS is far less lethal than it would have been 30-40 years ago due to greater understanding of the virus as well as effective anti-retroviral medicinal therapies. However, the biomedical model has nothing more to offer the person receiving or living with this diagnosis. Nothing regarding the consequences of changes in lifestyle that may be asked of them. Nothing of the stigma that people with HIV/AIDS may experience as a result of this diagnosis. A biopsychosocial model can encompass these other aspects of the diagnosis. Further, the biopsychosocial model makes room for a lack of human perfection, inherent though seemingly ignored in the biomedical model. Tracy explains:

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26 Tracy, "Hospice Care and a Theology for Patients at the End of Life," 260.
27 An immense issue of justice lies in the necessity of articulating “in first-world countries” in relation to this topic. However, this lies outside the purview of this paper.
In this model, the patient does not exist as an independent, atomistic machine; rather, the social existence of the patient and the reality that relationships can enhance or impair quality of life are taken into account. To note a further distinction, in the biopsychosocial model, vulnerability to illness and terminal disease is not interpreted as a problem to be fixed but is instead accepted as the very condition of human existence. Illness, aging, and death are all part of the human experience; there is no medical fix for this predicament.  

Emphatically, “this is not a fatalistic model centered on passive resignation.” Instead, it is an accurate assessment and naming of reality. Human mortality is a matter of nature; it is not a design flaw, and therefore should not be treated as such.

Aiming at Eternity

Despite its shortcomings, the biomedical model historically prevails in health care. In a system in which human bodies are viewed as being complex though ultimately comprehensible machines, it is reasonable to see how a doctor could come to view the death of their patient as a failure: there was an underlying problem that the doctor failed to identify in time, or the best treatment plan was not realized until it was too late. However, what this fails to appreciate is the limitedness of humanity. Death is not failure, though it very much can be conceived that way within medicine. “Indeed, one could claim that medicine—Western medicine, at least—is founded in a dream as old as humanity itself: to defer death. For death and the disease that is its harbinger are the most brutal reminders of the radical finitude of human existence.”

Medicine therefore becomes “an enterprise that keeps aiming at eternity precisely because of the sting of death.”

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28 Tracy, "Hospice Care and a Theology for Patients at the End of Life," 260.
29 Ibid.
31 Ibid.
Where are the conversations about what quality of life looks like to a person? What about identifying personal goals when total cure is off the table? When is it ok to say no? When is it ok to say no more? What happens when doctors are afraid of giving up on patients and families, and patients fear letting down their doctors and their family members, and families are afraid of letting go of a loved one who is ill? These are the human (and humane) questions of health care, ones often present though perhaps rarely verbalized. These are the questions that, at their core, are about human beings connecting with one another. All too often, these questions are topics that medical schools and other health care professional educational systems fail to cover in enough depth. The reasons for this are many and varied.

One aspect that bleeds into the way in which some doctors are formed and therefore how they practice medicine is the primary focus of the biomedical model of health care that is oriented toward preventing (in reality postponing) death as long as possible. Death is the enemy. According to this nearly vitalistic worldview, all life (any life) is deemed better than the alternative. This can easily devolve into patients becoming reduced to statistics, computations of how well the health care machine did or did not work in a given situation.

Part of the cause can be seen as the objectification of patients, a coping mechanism, that at some level, one needs in order to survive medical school. The first patients that first year medical students are exposed to are, quite often, cadavers. The dissection of human

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32 Vitalism is defined as “referring to the belief that the preservation and extension of human biological life (generally regardless of the conditions of that life) is a basic, fundamental, non-negotiable value. From this follows that the only morally justifiable reason for withholding or withdrawing life-prolonging medical treatment would be the conviction that such treatment cannot be useful or effective.” James B. Tubbs, A Handbook of Bioethics Terms (Washington, DC: Georgetown University Press, 2009), 183.
cadavers requires “a carefully maintained set of illusions and denial. Physicians and anatomy students must learn to think of cadavers as wholly unrelated to the people they once were.”

Further, this type of study “requires in its practitioners the effective suspension or suppression of many normal physical and emotional responses to the willful mutilation of the body of another human being.” It is difficult to postulate what effect this seemingly necessary objectification and critical distancing may have on young medical students at the beginning of their medicinal and professional formation. Certainly, these are valuable learning opportunities to study anatomy and practice various procedures. However, one wonders how this may unconsciously bias future doctors to take on a view that death is to be avoided at all costs. To this end, Bishop writes, “the first dead body that many medical students have ever seen is the cadaver, that anonymous person who has no social or psychological life, no family, no context. This patient is dead, and thus truly patient to the manipulations of medical knowledge. This dead body is the object from which medical students will learn in order to be of service to others whom they hope to keep alive.”

Bishop continues “Oddly, the dead body does not appear anything like the living body; death obscures life after all, yet it is death that is first observed. So the medical study of life originates with a decontextualized dead body; the body of the dead cadaver represents the bodies of the living.” In practicing for the first time on the dead, it is easy to see how life and death become starkly opposed to one another. If, for medical students, life and death are

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36 Ibid.
dichotomized, one the goal and the other the mark of failure. If students are learning to apply to living bodies what they learned from dead bodies, how are they being taught to interact with dying bodies?

From the Classroom to the Clinic

Countless studies have been carried out in order to investigate the perceptions of medical students and residents on their comfort with end of life matters. Virtually all of these studies indicate a level of unreadiness or significant apprehension in assessing when someone is realistically approaching the end of their life as well as initiating and carrying out this conversation with patients and their loves ones. In a survey of 2,287 medical school graduates in their residencies:

the large majority of residents felt very well or mostly prepared in medical knowledge and clinical skills such as collecting a history \((n=2111, 92.3\%)\), presenting a physical exam \((n=1969, 86.1\%)\), or pathophysiology \((n=1866, 81.6\%)\). In contrast, significantly fewer residents felt very well or mostly prepared for various applied clinical, professional, or psychosocial aspects of residency training…including providing end-of-life care \((n=954, 41.7\%)\), dealing with a patient death \((n=1059, 46.3\%)\), and practicing cost-effective care \((n=656, 28.7\%)\).

The hallmarks of the biomedical model of health care can be thus seen in the places where residents state they do or do not feel comfortable. Collecting a medical history from a patient or family member, performing a physical exam, and applying pathophysiological information all reside safely within the model of the human being, as complex machine, having a problem in its system that the resident must locate and intervene to fix. The less clear cut, more ambiguous topics of providing end-of-life care, “dealing with” a patient

death, and practicing cost-effective care all lack a specific problem with a singular solution to be found.\textsuperscript{38} End-of-life care and being present to a patient are both complexities that one must live into; they are not problems to be solved. They are vulnerable times that need to be handled with grace, sensitivity, humility, and a mindset of togetherness.

It is necessary to prepare formation for providers that encourages a reverence for the sacredness of all lives and all stages of life. Though many will specialize in various fields, it is important that providers do not become shortsightedly focused on only their specialty, blinded by the larger human story to which they are accompanying. One such example exists, likely unintendedly, in a short essay on the topic of teaching residents and medical students when a patient has died. The essay begins “The rare but occasional patient death is an unavoidable part of the facets of clinical medicine. Although an unpopular and rarely discussed subject, it is essential that cardiothoracic surgeons acquire the clinical skills to behave professionally and compassionately throughout the variety of clinical situations in which patient deaths occur.”\textsuperscript{39} Even when a patient does not die immediately in front of you, that patient still dies. Patient deaths are not rare. Health care must be viewed in the context of human life; it is not a human life in the context of health care. Health care needs to serve humanity. We must adapt our health care systems so that they may be beneficial at all stages of life, since needs change so dramatically. Our common humanity consists not only of body

\textsuperscript{38} Even the language of “dealing with” a patient death—rather than journeying with a patient’s death or even simply being present to a patient’s death—leaves something to be desired. Also, I believe that the lack of a possessive (patient death rather than patient’s death) is an example of the objectification that takes place in medicine so as to provide critical distance.

and mind but also is “formed by relationships, and for some, by a sense of the sacred.” Further, medicine needs to have “recognition of the frailty of human life, that humans are born dependent and in need of care, and will, in all likelihood, die dependent and in need of care.” The frailty of human life must not be understood as lacking agency or dignity. Human death is simply an aspect of human life. It is in these vulnerable transitions that patients and families can be most let down by the biomedical model of healthcare. These are difficult conversations, to be sure, but that makes them all the more critical.

Discomfort with the finitude of human existence and all that it entails is the major way that the health care system contributes to the negative image of death. Within this view also lies the idea that technology is to be worshipped as savior. When facing the limitations of the human body and human existence, two main courses of action emerge: acceptance and denial. Denial can take the form of abstraction, specifically in an over-reliance on and over-confidence in technology and technological pursuits, so as to “hide the broken body in a cocoon of technology.” Further, “when one is hidden in what is thought to be the necessary and protective barrier of medical equipment, there is distance created between the body as-it-is, and the body as shielded from the reality of pain, disease, and death. Concealing the compromised body can be perceived as a form of hostility toward the body.” One such example is a study entitled “A Virtual Out-of-Body Experience Reduces Fear of Death.” In the study, participants utilized immersive virtual reality technology.

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40 Tracy, "Hospice Care and a Theology for Patients at the End of Life," 260.
41 Ibid.
42 Ibid., 264.
43 Ibid.
Initially, they were able to see through their virtual body from a first-person perspective. Not only were the movements of the participants synchronized with their virtual body, but they were also connected tactilely, which is to say that when the virtual body was struck, the participant felt that sensation through vibrotactile stimulation of their physical body.\textsuperscript{44} Then the viewpoint was shifted from first person to behind and above the virtual body, giving a sense of an out-of-body experience. The results of the study indicate that “people who have had spontaneous [out-of-body experiences], not necessarily in the context of [near-death experiences] are also likely to have reduced death anxiety.”\textsuperscript{45} While this study is no doubt interesting, it further exists as an example of over-technologizing an inherently embodied, human, and earthy question.

\textbf{III. The Complexity and Necessity of “Both/And” Answers}

I can recall back to my first semester of graduate school as I began working on my Master of Divinity. My background, as I have alluded to earlier, is nursing. Much of my formal education up to that point was directed toward scientific pursuits, a world that is open to creativity and innovation, yet is also grounded in evidence-based practices and singular explanations and deductions. As such, I was accustomed to “either/or” type answers: if A is known to be true, B is therefore false. Needless to say, I experienced quite a culture shock when beginning to study theology and needing to answer questions such as ‘Is Jesus fully human or fully divine?’ It was a radical change to switch from an either/or mindset, in which the world presents itself as clear cut, black and white. Instead, I recall


\textsuperscript{45} Ibid., 13.
realizing a trend that in theology, whenever an either/or question is presented, the answer is generally and perplexingly instead “both/and.” Jesus is both fully human and fully divine. The Christian monotheistic God is triune. Two things that should in all reality and according to common sense be mutually exclusive opposites are in fact two different parts that together create one whole. More importantly than that even, together they provide a richness and a depth of meaning that neither one could achieve on its own.

Summer and winter can be quantitatively as well as qualitatively described as opposites. However, are they not simply both parts of seasons that make up one year, mirroring the seasons that we experience in life of growth, thriving, letting go, and resting? These cycles occur in nature, and they occur in our lifetimes as well if we learn to appreciate the many gifts we receive from each season.

Strength and weakness exist in definitional contradiction to one another. However, I have always found the most strength in people who had the courage to show and share their own vulnerability, their own weaknesses, therefore showing up with their full authenticity, their full strength. Within true strength, there lies the existence of an appreciation of weakness, for it is actually a show of a weakened and fragile façade if one is only able to claim strength. They each inform the other. They each ask more of the other. They each draw out more of the other.

Beauty and tragedy, as well as joy and sorrow, seem as though they should be experienced individually, but quite often we find them interwoven into one another. We can speak of the bitter-sweetness of life when we leave one job or home to move on to another
experience or adventure, meaning that there is some pain involved in moving forward into an otherwise positive situation. There is also room in the human experience for sweet-bitterness when we mourn a loved one whom we have lost yet taking courage in the fact that they will no longer experience pain. There is some balm in this understanding, though it rarely fully satisfies the aching of their absence. The bitterness of pain still exists in the ones left behind, potentially sweetened by the love shared over a lifetime together.

Life are death are equally false dichotomies. It is life and death that comprise and structure humanity. Though it seems intuitive, we never actually experience one solely. We are never exclusively alive in the same way that we are never exclusively dead. Our bodies, our spirits, our minds are continually traversing and navigating the large gray area in between the two poles. Our cells, the building blocks of our humanity, live and reproduce and die throughout our days, months, years, and decades. We are being continually made new, reborn. This implies a continual experience of letting go, of letting pass away.

“Comprehending death, one comprehends life”46 Hair on the head and body, skin, nails, and teeth are the outward facing body parts that we experience in one another, and they are essential parts to our humanity, to who one is as a person. However, the five parts of this list—the ‘person’ we see—are all dead! Hair of the head and body lives only at its roots; we see dead hair. Nails that we see are dead nails; the quick is painful and hidden. The teeth, all that is visible, are dead, and their tender living roots we only experience painfully from time to time. Outer skin is dead—horrible if it was not, for it is sensitive enough already…So when we get excited about a physical

form—someone else’s body—we are stimulated by impressions of what has died already.\textsuperscript{47}

It strikes me to note that everything in this list that is tied to life is equally tied to pain. The balance—the way we live out this “both/and”—of alive and dead allows us freedom from pain.

Life and Death and the Both/And Answer

The intrinsically interwoven nature of life and death can also be seen in that humans are able to describe degrees of aliveness, often worded in a sense of blissful transcendence as “I feel so alive!” How intriguing that this notion of one’s liveliness, the strength and vitality of their life force, is customarily expressed when choosing and completing an activity that made real one’s chance of dying—skydiving, cliff jumping, or running with the bulls in Pamplona, Spain. What ties these experiences together is that they raise a person’s pulse, respirations, and adrenaline. In short, they look death in the face at the same time that one is feeling the strength of their beating heart, the renewing breath of air in their lungs, the electrifying pulse of their body fully alive.

In attuning to the miracle of both the human body and the human being, these are moments of transcendent bliss. This same level of vitality is possible through other means, specifically by facing, claiming, and integrating the fact death is truly a part of life. The key is the meditation on both the blessedness and the brokenness of one’s body and one’s life.

\textsuperscript{47} Bhikkhu Khantipālo, as quoted in Todd LeRoy Perreira, ““Die before You Die”: Death Meditation as Spiritual Technology of the Self in Islam and Buddhism,” \textit{The Muslim World} 100, no. 2-3 (2010): 257.
IV. Theological Anthropology and Human Freedom

By leaning into and embracing the added richness of the both/and answer, along with the fact that it is in giving (and even giving up) that we receive, we come to the vision of theological anthropology of John Randall Sachs, S.J. Our shared anthropology, indeed our shared and sacred humanity, is marked by human freedom. It is our freedom that distinguishes humanity from the rest of creation; it is our freedom, gifted to us by God, that allows us to live and move and have our being, to live in the image and likeness of God. “Freedom is from God and for God. On its deepest level, it is the capacity and responsibility to be in loving relationship with God. It is the gift of love, the capacity for love, and it finds its only true fulfillment in love.”48 Ordinarily, freedom is equated with limitlessness and boundless potential. “Intentional agency is the basic experience of freedom…On its simplest level, it presupposes real options and the ability to choose from among them what it is I decide to do.”49 However, if freedom exists in connection to our relationship with God since it originates as a gift from God, to be true freedom, it must be covenantal. This covenant exists between us and God as well as one another. It is fundamentally tied to our vocation—who and how we are meant to be. “Freedom is the capacity to choose who I am going to become as a person. Life is not only a gift, it is a task as well. We are not merely objects thrown into existence, determined by others and outside influences.”50

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49 Ibid., 29.
50 Ibid., 29-30.
According to Sachs, freedom is not finally about choice, as freedom is often understood. It is about choosing, and, more importantly, having chosen, whole-hearted living. “While freedom certainly entails the ability to change one’s mind or to have a real change of heart, its goal is not infinite options or endless revision. As a matter of fact, change just for the sake of change is often a sign of immaturity or great unfreedom.”51 Further, “in many respects, we are freest when, no longer torn in different directions by the multitude of possibilities, we can at last surrender to one of them whole-heartedly.”52 We are most free, experiencing humanity as humanity was intended to be, when we can choose, and we can commit. As such, there is great freedom in limitedness and great bondage in boundlessness. In commitment and whole-hearted living, we are able to embrace the limits we experience, for saying ‘yes’ to one option is consequently and inevitably saying ‘no’ to a myriad of other options. It is important to grieve when necessary what is left behind in the choices we have made. However, there is much to rejoice in being freed from the pressure of needing to do it all.

Why should humans have to experience these losses and the limits they represent? As Irenaeus writes, “Someone might say, ‘Why is this? Was God unable to make humanity perfect from the start?’ He should realize that because God was not born and always remains the same, he can do anything, as far as depends on himself. The things he made had to be lesser than himself, however, precisely because they were made and have a beginning.”53

51 Ibid., 31.
52 Ibid.
There is a fundamental distinction between creator and created. Living within our humanity involves living without unlimited choices. This is God’s artistry. Bearing the marks of the creator, we are meant to live our best lives. We have been shaped from the clay of the earth, imbued with the breath of God.

If you are God’s artifact, then wait for the hand of the Master which makes everything at the proper time, at the time proper for you who are being created. Offer him a soft and malleable heart; then keep the shape in which the Master molds you. Retain your moisture, so that you do not harden and lose the imprint of his fingers. By preserving your structure, you will rise to perfection. God’s artistry will conceal what is clay in you.  

It is God’s design for humanity that we be finite. As finite beings, we can live most fully when we let go of what we cannot control, we face what scares us, and we embrace the beauty of the sacred.

Life and Death and Freedom

An essential human task is not only the recognition of but hopefully the appreciation of the inherent limitedness of humanity. This is not meant as a judgment or condemnation on humanity. In fact, the innovation, creativity, intelligence, community, and love within humanity can truly be astounding. However, we are fundamentally mortal, finite creatures. Much of our lives we try to live in opposition or ignorance of this fact. However, true freedom comes in realistic assessment of one’s conditions and in whole-hearted commitment to one choice. Humans cannot live forever. Why then do we pretend anything different than this is true? In failing to come to terms with this fact, we continue to live in great unfreedom, in which we are mesmerized and enamored by the seemingly endless,

\[54\] Ibid., 27.
boundless opportunities in front of us. This is superficial living. This is not how a person grows roots or grows rooted to the person God has created them to be. With commitment and choice, we will necessarily say ‘no’ to some things. Leaving these options behind, we may then in freedom open our lives fully to what it is that God calls us. In understanding that we are born out of love and that we will return to that same love in our death, Henri Nouwen states in an interview with the *National Catholic Reporter* in 1994:

> I am trying not to think any more about the questions such as ‘What can I still do in the years I have left?’ or ‘How much can I still accomplish?’ For me the question is changing from ‘How much can I do before I die?’ to ‘How can I live these coming years in such a way that my death will be fruitful? I ask ‘How can I prepare myself for death in such a way that my spirit, the love—that part of me that is of God, that part of me that is my soul—continues to inform the human family?’

To some, coming to terms with their own limitedness may sound like giving up hope. On the contrary, that perspective carries the tone of being blindly optimistic. That perspective sets up an understanding that humans are chained to death. Death is a punishment, the ultimate enemy to be avoided. Death exists as the detriment to life, according to this point of view. This is what Dr. Ira Byock describes as an “imaginative deficit” in which people cannot imagine anything worse happening than someone dying and cannot imagine anything of value happening within the dying process. This stays willfully ignorant of the fact that the singular event that every human will experience at some time is death. Death is a part of life. It is part of what it means to be human. Death is not a burden to which we are chained. It


56 Dr. Ira Byock, "Living Well until You Die: An Evening with Ira Byock" (Presentation at the Minnesota Network of Hospice and Palliative Care, Bloomington, MN, April 9, 2018).
will eventually meet us all. We wear our death in our very bones.\textsuperscript{57} Meanwhile, our life courses through our veins, and fills our lungs, the very breath of God in the form of spirit. It has been a part of us all along, as has the life within us.

In the true freedom that embraces our limitedness, we are able to love greater, more intensely, more presently, without conditions, without pretense. When we accept the way in which we have been created, we can love one another more fully into God’s vision in the time we have together.

\textbf{V. Pastoral Christological Considerations}

“We all walk toward death and call this ‘life.’
The Gospel of Mark…is the story of how Jesus brings life as he walks toward death.”\textsuperscript{58}

The work that I have done and will continue to do for the foreseeable future in hospice has already changed the way I see the world. For instance, this year, I experienced Good Friday in a much different, and in fact deeper, way than ever before. In the church that my family attended as I grew up, every Good Friday service, we chanted and meditated upon the Taizé community’s “Stay with Me.” The repeated chant draws one deeper and deeper into the words: “Stay with me. Remain here with me. Watch and pray. Watch and pray.”\textsuperscript{59} I remember interpreting these words as Jesus’ stern instructions to me that I remain vigilant in my faithfulness to him. I did not want to disappoint Jesus in the same way that the disciples failed him.

\textsuperscript{58} Ibid.
Through my work in hospice, I experienced the humanity of Jesus this past Holy Week in a stronger way than ever before. On Good Friday, I saw the face of the man I had met for the first time that afternoon who would eventually pass away that evening. I saw his face as I heard Jesus’ words in this song. This man had been nonresponsive; I had and have never heard his actual voice. But he, within hours of his own death, seemed to have the same request: Stay with me. Be present here with me. Don't leave me. Wait with me in the stillness, the thinning of the veil. Jesus utters this same sentiment to Peter and the two sons of Zebedee as he prays in the garden of Gethsemane: “I am deeply grieved, even to death; remain here, and stay awake with me.”

Experiencing the pain and anguish of what he knows is to come, Jesus reaches out to his disciples, asking that they keep vigil there with him, asking so that he does not have to experience this alone. Jesus foretells his death multiple times throughout his ministry. Yet as Jesus faces his death, he shows true human vulnerability in his fear as he prays in Gethsemane: “My Father, if it is possible, let this cup pass from me; yet not what I want but what you want.” In the hour of his death, Jesus is unafraid of connecting with God out of the authenticity of his fear. His first request expresses anxiety and questioning; the second affirms his faith in God. He is experiencing a muddled mix of both uncertainty and certainty in a truly human way in the face of his own death. In this way, in this mix of fear and hope, I have heard the tone of Jesus come through in the words of so many people facing their own death. This is where incarnational theology births solidarity and compassion in an untold

60 Matthew 26: 36-46, NRSV.
61 For example, see Mark 8:27-9:1; 9:30-32; 14:27-31.
62 Matt. 26:39, NRSV.
way. Jesus truly lived. He loved. He healed. He worked for justice. And he died. I find
tremendous hope in a God who can understand joy and suffering through true embodiment.
Jesus provides salvation, makes possible resurrection for each of us in his death. However,
the manger is the true miracle, as divinity takes on human flesh. To be fully human, once
born, Jesus’ death was compulsory. There is significant theological meaning-making to be
carried out within the way we understand his dying, death, and resurrection. However, the
incarnation changed what it means to be human, for the definition of human needs to
expand to fit Jesus Christ. Our humanity is made more blessed, even more sacred because
Jesus lived.

VI. A Theology of Hospice, A Theology of Hope

In many ways, hospice care exists in counter to the prevailing health care culture.
Hospice care falls under the umbrella of palliative care. Palliative care is “medical care or
treatment that is focused upon ameliorating the symptoms (e.g., pain, discomfort,
 depression) of a disease or condition rather than being curative.” Etymologically, palliative
care links back to the Latin word *palliare* which means to cloak or to cover with a cloak,
which supports the understanding that palliative care is directed toward comfort and coming
alongside another in need. Palliative care and its undergirding values support holistic,
wellness-based health care. Palliative care understands that people are more than just their
physical bodies. Further, palliative care affirms that quality of life, which can only accurately
be self-defined, matters. The main distinction between hospice and palliative care is that

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63 Tubbs, *A Handbook of Bioethics Terms*, 121.
palliative care can be used concurrently with active treatment. In contrast, a person is eligible for hospice care when their prognosis is assessed to be less than six months, and when they will no longer be pursuing treatment for their terminal disease.

Hospice is, therefore, a specific type of palliative care. The goals of active and even aggressive symptom management as well as holistic—physical, emotional, spiritual, and social—comfort are shared between palliative and hospice care. “The word hospital and the word hospice share the same etymological source: the root word _hoste_, a word that means both guest and host. From this source, the word ‘hospitality’ is derived, a word that connotes positive reception of guests.” Further, “All three of these terms, hospital, hospice, and hospitality concern relationships with the stranger, in some cases the unbidden, unwelcome stranger.” Hospice involves many ways in which one meets the stranger. We all are to meet death as a stranger in some capacity. Further, in my experience, hospice patients have described an experience of their own body becoming a stranger, as they feel betrayed and let down by their body’s failing. Likewise, pain, and in particular pain that cannot be pharmacologically controlled, specifically of the emotion, social, and/or spiritual variety, “can be interpreted as the uninvited, even unwelcome, stranger that demands a response. The ‘stranger’ is not necessarily separate from us; rather, when one experiences bodily pain one can perceive one’s own body as a site of alienation, even invasion.”

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64 For instance, a person with a diagnosis of cancer of some kind can receive active, aggressive chemotherapy with the goal being treatment and/or cure of their cancer. This person may also receive care from a palliative care specialist that would seek to manage the harsh side effects of chemotherapy, such as intractable nausea. In this way, active treatment and palliative care are used simultaneously.
65 Tracy, "Hospice Care and a Theology for Patients at the End of Life," 259.
66 Ibid.
67 Ibid., 263.
In Tracy’s piece entitled “Hospice Care and a Theology for Patients at the End of Life” she establishes a model, which explores potential responses to terminal pain. She describes three responses: hostility, hospitality, and hosting. Tracy identifies these three responses in relation to terminal pain specifically. The argument that I establish here is that this model works equally well in relation to death itself.\footnote{That is to say that the way people relate to their own mortality or the impending death of a loved one, which is in part related to fear of death and death anxiety. This would certainly fall within the larger category of pain that Tracy describes on page 262 as “total pain” which “includes a spiritual dimension.”}

The hostility response is often tied closely to the biomedical model of health care. “War-based language is often used to frame a plan of care or conversation about symptom management. There is a ‘battle to be won,’ a patient chooses to ‘fight,’ a tumor will be ‘destroyed,’ disease is the ‘enemy,’ and death is a ‘foe’ to be fought as well.”\footnote{Tracy, "Hospice Care and a Theology for Patients at the End of Life," 263.} The foundational values of this response include “agency, power, and resistance.”\footnote{Ibid.} However, when responding with hostility, there is the potential for significant collateral damage. In the field of health care, much needless suffering can be experienced as a result of pursing aggressive treatment at all costs. Tracy asks, “What is the value of fighting the ‘battle’ against disease when one is alone, exhausted, and exiled from home?”\footnote{Ibid., 263-64.} What does a person make of their quality of life when their emotional, mental, social, and spiritual wellbeing are suffering for the sake of potentially futile attempts at recovering physical health? Death anxiety as manifest by unwillingness to accept reality and the limitations of one’s own
mortality is a form of significant spiritual pain, potentially leading to many questions regarding theodicy.

On the other extreme is the response based out of hospitality. Instead of war-based language, the hospitality response involves “language of resignation or merit, that one must graciously accept one’s pain, with deep connections here to Christian theologies that glorify suffering, or assert that one in some way deserves one’s pain.”72 Further, this approach can use “the language of ‘meaning making’ or the language of God’s foreknowledge of and role in one’s suffering.”73 For some, this can be a theologically and spiritually productive understanding and framework when applied to their own situation. It does, however, have the potential to be abused, for instance, when one is applying this notion to another person, specifically someone who is does not have the ability to self-advocate. It also has the potential to lead to maladaptive and shame-based theologies as well as self-conceptions.

In reaction to these two non-ideal options, Tracy offers a third way, a tertium quid, which is to respond to pain as she argues or to the idea of one’s own death, as I argue, with the action of hosting. “The concept of hosting pain does not involve militaristic approaches to clinical care (responding with hostility) or sweetly enduring pain (responding with hospitality); instead, hosting pain can be interpreted as allowing a strange presence to exist within you without having to strenuously fight this presence or having to warmly greet it”74 “Hosting pain does not mean passively accepting its presence; it instead means recognizing

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72 Ibid., 264.
73 Ibid.
74 Ibid., 263.
the limits of one’s ability to remove it.”

We cannot escape death. We will all have our final exhalation, a last cleansing breath, in this world someday. However, with the language of hosting, we can accept and integrate that fact, while still with agency, living into the vision that God has given to each of us in love. Hosting offers the chance to name the pain and grieve the losses related to our limitedness by not denying the reality of death’s presence.

Hosting allows room for both the positive and the negative to reside side by side. In the great holy and sacred mystery of the way we enter and exit this world, when the veil between this world and what exists beyond becomes most thin, beauty is commonly interwoven with heartbreak. We can simultaneously shed tears out of both relief and anguish. We rarely experience emotion singly. In this way, “hosting also allows for responses such as gratitude that someone has died, a response that can be surprising and unsettling for some, leading to guilt and confusion” if left unchecked or experienced alone. The language of hosting, the language of both/and, allows for and can properly hold the complexity of the human condition, as we live in relation to one another and to God.

I have been a hospice nurse for approximately six months at this time. It has already altered the way that I see the world, which I believe is due to how counter-cultural the concept of hospice is. Though it takes little of the sting of loss away, it has radically altered the way I view both life and death. Life is more precious. Death is more natural, less fearful.

In tying all of this together, hospice accurately and appropriately names that humans are finite creatures. It is built around this fact, rather than existing in blind denial like some

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75 Ibid., 264.
76 Ibid., 265.
areas of health care seem to. We all wear our death in our bones each and every day of our lives. Hospice offers a new vision that can combat the fear of death and fear of the unknown that so many experience. Hospice offers the opportunity that no one has to make this last leg of their journey alone. Some accuse hospice of being about helping people die. No, rather hospice is fundamentally about helping dying people to live. By virtue, the hospice interdisciplinary teams support the physical, mental, emotional, social, and spiritual health of the patient and the family. Further, hospice is a supreme example of the incorporation of the both/and answer. Hospice is about both holding on to hope and ensuring quality of life along the way. This type of hope is strong in a different way than that hope that says, “let’s try another round of chemo.” Hope gets rewritten to be an affirmation of the goodness of humanity. This type of hope states that human life is a precious, fragile, embodied, emboldened gift from God. Hospice slows down from the frantic pace of ordinary life, as we sit in sweet stillness with our own humanity, with one another, with God.

When given the opportunity, why not embrace all of what life has to offer which includes living through the mystery of the dying process? Dying is not the end of life; it is simply the beginning of whatever we believe to come next. I believe it is a homecoming. My hope at its care is to provide a different image or a different way to relate to not only to one’s own mortality and death, but also to one’s own life and humanity. May you attune to the very blessedness of your breath and your body, and may you find peace all the days of your life.
Bibliography


Byock, Dr. Ira. "Living Well until You Die: An Evening with Ira Byock." Presentation at the Minnesota Network of Hospice and Palliative Care, Bloomington, MN, April 9 2018.


