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Destigmatizing Death: Engaging Healthy Emerging Adults in End-of-Life Conversations through an Undergraduate Palliative Care Curriculum

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a thesis submitted to the Faculty of Emory College of Arts and Sciences
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Abstract

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Western culture proliferates the myth that conversations about palliative care and death can only occur at the end of life. Typically, such communication does not occur until it is too late—after life-limiting conditions present. However, dialogue about these difficult topics proves to be a crucial component of development in emerging adulthood (18-23-years old). Emerging adults are not immune to terminal illness, and many eventually become substituted decision-makers for their loved ones, forcing them to confront end-of-life decision-making. According to recent statistics released by the Centers for Disease Control, each year more than 11,000 adolescents and young adults (15-34-years-old) die from chronic illnesses. To decrease anxiety and fear about the end of life, the American Academy of Pediatrics and World Health Organization recommend having conversations with terminally ill children and emerging adults about decision-making as soon "as they are developmentally and emotionally ready" (Pao and Mahoney 511; Wiener et al. 898). However, despite these statistics and recommendations, end-of-life conversation is largely avoided with healthy emerging adults.

This honors project assesses the efficacy of a palliative care curriculum recently piloted for undergraduates at Emory University. Early interventions in educational settings—relying on resources typically used in advance care planning—may prove important in empowering healthy emerging adults to make well-informed decisions about their end-of-life care. While there is currently a wealth of literature showing the importance of end-of-life conversations with young adults suffering from terminal illnesses, the research—quantitative and qualitative—about communication with healthy emerging adults is lacking. This honors thesis bridges that gap by gauging both the pragmatic awareness of planning tools, and the effectiveness of an undergraduate curriculum focused on humanistic discussions about death.

As explored in the results, the foundations of palliative care—and its academic intersection at the nexus of humanities and science—play a key role in educating emerging adults about decision-making at the end of life. With an interdisciplinary emphasis, an undergraduate course is ideally positioned in the life of an emerging adult to discuss future wishes and begin to catalyze a societal perspective shift towards the end of life.

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And, of course, to my mom and dad—my educational and personal growth and success would not have been possible without you. This thesis is a culmination of and reflection on many Shabbat dinner table conversations, deep late-night dialogues while walking Pax down Greenleaf Ave., frantic phone calls from overseas, and midday calls from the library. Thank you for imparting your collective knowledge and passion for helping others during their most vulnerable moments unto me. I can only hope to achieve what you both have during your lives. I am excited to venture onto the next phase of my life with you both. I love you.

After struggling through writing assignments and English papers in high school, it is hard to imagine that I have written a nearly 100-page academic honors thesis. However, because of the incredible mentorship of professors, teachers, advisors, friends, and family, I have completed a thesis I am beyond proud of. Thank you all for the immense support. Happy reading!

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CHAPTER ONE: INTRODUCTION

I, DAVID REUBEN GIDON KULP, a resident of the State of Maryland, hereby appoint my parents, GIORGIO VICTOR PAUL KULP and DEBORAH JEAN SNYDER, as my Co-Agents to make health care decisions for me pursuant to the Health Care Decision Act and as set forth below. I desire that my wishes as expressed herein be carried out through the authority given to my Agent by this document despite any contrary feelings, beliefs or opinions of members of my family, relatives, friends, conservator, or guardian. If at any time there are Co-Agents serving hereunder, action may be taken by either Agent acting alone. The powers granted to my Agent hereunder shall be immediately effective, except as hereinbelow noted.

The subject line of the email that flashed across my inbox read, “send me signed document i sent u the other day—the one about power of attorney.” The only line that followed in the body of the email elaborated, “please sign this and send it back to us.” In her typical fashion—the message written clearly in the subject line with no punctuation or capital letters—I knew the familiar sender immediately: my lovingly concerned mother, of course. I could only presume she was up late, concerned about my well-being, and brainstorming ways to comfort me while I was living abroad. The attached document—my advance directive—had the entirely opposite effect on my psyche. The tragic events that preceded my mom’s email had likely triggered both of our anxieties, leaving us equally fearful for the future, or lack thereof.

Rolling out of bed and staring into my iPhone screen, the email appeared early one morning in December 2015, during my gap-year abroad in Israel before matriculating to Emory. I was nearing the completion of my first semester, preparing for first responder EMT training with Israel’s national emergency medical service, and ultimately moving to serve in a small development village. Amidst the excitement of training to become a medic and serving my community, I knew the reasoning for my mom’s email. The month prior, on November 19, 2015, an old bunkmate of mine from sleepaway camp had been killed in a roadside shooting, a terrorist attack perpetrated just a few miles from where I was living in Jerusalem. Just as I was, Ezra was taking a gap-year before college, developing meaningful friendships, and exploring a new culture. His time, however, was cut short. Too short.

Having received the confirmation of Ezra's death, I vividly remember calling a friend to share the news. As a largely sheltered, innocent, and privileged 18-year-old at the time—with little personal experience with death—I never imagined having to deliver such horrific news, much less live through it in such close proximity. Until that moment, I had never experienced death personally. I have four living grandparents and two engaged and living parents. Given my age, psychosocial circumstances, developmental trajectory, and some luck, I had been largely shielded from significant loss. I had worked previously in high school with children living with chronic illnesses, but never experienced a death of a friend or camper until a few years into my emerging adulthood. The only personal experience I could pinpoint of relevance to me was the death of my childhood best friend's mother from cancer when I was 16 years old in the tenth grade. Her death was my first personal experience, my first funeral, and my first *shiva*. While I was certainly deeply shocked and saddened by her sudden passing, I was surely more focused on supporting my friend as he adjusted to life without his mom, a pillar of our community. Similarly, given my parents' vocations in pediatrics and psychiatry-oncology, there was regular conversation about morbidity and mortality around the dinner table. However, these conversations were yet again once removed, in that I never had personal contact with individuals in their narratives. The dialogue, rather, involved rational and deliberative thought and analysis around the tragic deaths of *their* patients, of *other* people, in *distant* places.

Ezra's death had shattered my innocence and forced me to confront death directly. The goal of my gap-year was to be reflective and turn inward, without undo external pressures, encouraging me to think conceptually and deeply about existential questions and notions pertaining to matters of life and death. Ezra's death was a natural precursor—it laid the groundwork and brought into bolder relief the seemingly distant concepts of mortality. Donning my standard-issue EMT flak jacket and Kevlar helmet, I understood the urgency of my mom's email. Training in triage and trauma medicine, I was thrust into a world of stigma and taboo surrounding death. And the advance directive attached to my mom's email suddenly forced me to confront my own finitude and the real potential of my own end.

As I glanced over my advance directive at the time—and now again while researching this thesis project—I realize the gaps in my knowledge and understanding of such an important document. I never had discussed my wishes for the end of life with my parents. At the time, I had not discussed what "appropriate life-sustaining procedures" they would advocate for in a case that I was unable to make decisions for myself. I had not voiced whether I would want them to pursue artificial feeding, hydration, mechanical ventilation, or resuscitation, if it came to those highly unfortunate circumstances. I had registered to be an organ donor when I received my license in high school, but never spoke to my parents about the process of making "anatomical gifts." Would the ideologies and desires of my parents align or conflict with those of my own? I had also never thought about how I would want to be remembered. Did my parents know my wishes for a celebration at the end of my life? I had skimmed the six-page document of highly sophisticated legal language, signed it, and sent it back to my mom. I then filed the document away in the depths of my hard drive, never to be approached or spoken about again in person.

After transitioning to Emory, what intrigued me most about my liberal arts education were the conversations about existential ethical and philosophical questions. I began exploring the contentious and often opposing narratives in bioethics and disability studies literature. This further fueled my passion for decision-making at the end of life and within vulnerable populations. Ethics slowly became a passion I could easily see applying to my career as an aspiring physician. Drawing from my parents' work at the intersection of pediatrics, psychiatry, and terminal illness, I explored the realm of palliative care and end-of-life decision-making. I struggled with questions of autonomy and beneficence: Are minors able to understand the risks and benefits of end-of-life decision-making? Can emerging adults understand their delicate medical situations and the consequences of their actions? Can adolescents rationally engage in deliberative thought? How do psychosocial variables, neurological development, and underlying values impact decision-making? These questions, amongst many others, began to percolate for me over the last four years, serving to become the crux of my Interdisciplinary Studies major and narrowing my current interest in palliative care.

It is not atypical, in my personal experience, for friends—my age and older—to pause when I share that I am interested in palliative care. "Palliative care" has a certain weight to it, often perceived to be too heavy for an emerging adult to hold and process. Many of my peers, still coming off the heels of perceived adolescent invincibility, avoid conversations about death and dying altogether. This aversion stems from a deeply rooted stigma in Western culture. Given advances in healthcare and prolonged longevity, the natural course of death occurs at later ages. As such, healthy emerging adults are often hesitant to discuss taboo topics in an effort to ward off death itself.

As the only definitive aspect of life, however, it is crucial to confront the certainty of death. Aversion of the topic altogether has the opposite effect and ultimately influences how society treats, cares for, and interacts with those who are dying, whether it be the terminally ill, the elderly, or healthcare professionals trained to treat both those aforementioned populations. Lack of openness before chronic and terminal illnesses present over the course of a lifespan continues to drive stigma, and causes for incredible mental, emotional, and physical anguish at the end of life.

This thesis aims to counter that stigma through an innovative pedagogical model for integration of palliative care education in an undergraduate setting with healthy emerging adults. The thesis is grounded in interdisciplinary thought at the nexus of history, ethics, psychology, linguistics, and philosophy. Chapter Two delves into an evolution of palliative care through a literature review, grounded in a history of the hospice movement and palliative care medicine specialty. Through a firm understanding of the history of palliative care integration in pediatrics and emerging adulthood, much can be learned about how medical professionals speak with chronically and terminally ill young people, informing ways to engage healthy individuals. Understanding historical Western medical practice can shed further light on the entrenched social stigmas and fears, both conscious and unconscious, towards discussing death and dying. Visualizing the gaps in clinical care can inform educators how to best design holistic and safe spaces for discussing historically taboo topics. Lastly, analyzing decision-making with an ethical lens provides insight into core pillars of autonomy and beneficence in medical care.

A brief word about definitions: After reviewing current literature, “emerging adulthood” has been broadly characterized as the transition from adolescence to adulthood defined from 18- to 23-years-old, the demographic of individuals surveyed in both the feasibility study (see Chapter 4) and for this honors thesis study (see Chapter 6). The range for “adolescent and young adult” has been heavily debated in the context of pediatric and adult oncology and palliative care literature, and is slightly different to how “emerging adult” is defined for the purposes of this thesis. At the moment, the National Cancer Institute identifies the range of 15- to 39-year-olds to be defined as “adolescents and young adults.” Though some have adopted a shorter range, most

U.S.-based medical institutions have adopted this range to define emerging adulthood broadly. However, that range is debated on an international scale. Various medical institutions in Europe and Canada define this range from 15-29-years-old. Dr. Sylvie Aubin at the Sir Mortimer B. Davis Jewish General Hospital in Montreal proposes subdividing the clinical definition that NCI defines: “early young adulthood (15–18 years old), young adulthood (19–24), and late young adulthood (25–39)”(“What Should the Age Range Be for AYA Oncology?”). This thesis focuses on and aims to evaluate loosely the “young adulthood” demographic—the average age encapsulating the majority of undergraduate students enrolled at Emory University—and characterizes that range as “emerging adulthood” in this thesis paper.

Turning to psychological development, Chapter Three explores the typical adolescent and emerging adult brain and subsequent stages of death awareness. Insight into an emerging adult’s conceptualization of mortality—and early death perception—provides further framing from which to best engineer an undergraduate course in palliative care. Chapter Four turns to focus on engaging healthy emerging adults in advance care planning—adapting current tools for the classroom that are used with terminally ill individuals. It also explores methods of engaging healthy individuals in community gaming around challenging conversations. The chapter concludes with a feasibility study conducted in Spring 2019 to better understand the relationship of undergraduates at Emory with palliative care-related tools and terminology. This study serves as preliminary data to justify a palliative care, meaning-centered educational curriculum in an undergraduate setting, and for this subsequent honors thesis project.

With a grounding in literature and data presented in the aforementioned chapters, Chapters Five and Six explore the development of the IDS 205W pilot course, *Science and the Nature of Evidence: Death, Dying, and Finding Meaning,* taught during Fall 2019. Innovative collaborations between faculty in the Division of Palliative Medicine and Institute for the Liberal Arts paved the path for a grant from the Arthur Vining Davis Foundations to integrate the foundations of palliative care into the undergraduate curriculum. This partnership serves as the crux of this thesis—the evaluation of a course piloted for healthy emerging adults. Through the interdisciplinary course content, the class was developed to address the profound distress that accompanies decisions at the end of life when they are not clearly articulated prior. Qualitative and quantitative results signal a potential solution to decreasing stigma and fear, and enhancing autonomous decision-making amongst younger and healthier populations. As described in the results in Chapter Six, and in the following discussion in Chapter Seven, prolonged engagement with healthy emerging adults in an undergraduate setting may prove helpful in shifting the deeply rooted aversions towards death and dying in Western culture.

One thing is guaranteed: if one waits until the moment of death to confront it and understand its essence, it will surely be too late. An undergraduate educational curriculum may prove helpful to facilitate approaching the subject of death and dying in a safe and structured environment. This environment should promote deliberative thought and the integration of substantive issues to encourage emerging adults to seriously face the end of life. His Holiness the Dalai Lama says, “It is crucial to be mindful of death—to contemplate that you will not remain long in this life. If you are not aware of death, you will fail to take advantage of the special human life that you have already attained” (His Holiness the Dalai Lama 39).

CHAPTER TWO:

EVOLUTION OF PALLIATIVE CARE IN PEDIATRICS & ADOLESCENCE: A LITERATURE REVIEW

The History of Hospice & Palliative Care Medicine. To best assess the importance of developing a palliative care curriculum within an undergraduate setting, it is crucial to understand the history of the subspecialty in the context of the Western medical system. While the prospect of discussing terminal diagnoses directly with children, adolescents, and emerging adults is a relatively recent paradigm, the notion of caring for dying patients existed long before the development of the pediatric palliative care specialty. In fact, the palliative care movement was originally pioneered by Drs. Dame Cicely Saunders and Elisabeth Kübler-Ross as early as the 1960s (Marston). With a belief that the patient remained at the center of care—particularly at the end of life—the hospice movement was born. Saunders, the 'grandmother' of palliative care, founded St. Christopher's Hospice in south London in 1967, emphasizing compassionate care and pain management in the context of serious illness ("Dame Cicely Saunders: Her Life and Work"; American Public Media). She believed that rather than 'forfeiting the fight' and giving up on the patient, as so many hospital physicians did, hospice could act as a place where "so much more [could] be done" to care for the patient and their family. Holistic care would recognize the "practical, emotional, social, and spiritual" needs of the patient, thus elevating patient-centered care at the end of life ("Dame Cicely Saunders: Her Life and Work"). This ethos of humanistic connection and holistic care remains as the core foundation of palliative care today, largely concerned with providing care upstream from diagnosis of a serious illness as well as symptom management at the end of life.

In 1976, the Connecticut Hospice, the first hospice in the U.S., was founded by Dr. Florence Wald—"the mother of the American hospice movement"—with support of two pediatricians and a Yale University chaplain (Marston; Rierden). This collaboration catalyzed a shift in the hospice movement to include children and adolescents with terminal illnesses. It also signaled a revolutionary shift in the scientific and biomedical communities to fund projects investigating the validity and effectiveness of pediatric palliative and hospice care, both in dedicated hospice centers and at home. In fact, *The New York Times* featured a special in April 1977, recording the efficacy of home care for dying children through a federally funded project at the National Cancer Institute. Dr. Ida Marie Martinson aimed to aid families with the care of children suffering from terminal cancer. The study showed that it was not just "feasible for families to care for dying children at home but it is also much easier on the families' psychological adjustment and far less costly than hospital care" (Brody 1). Parents acted as "primary care givers," which ultimately helped "parents to realize that they have done all they could" (1). Such child-centered care that focuses on the wishes and environment of the child at the end of life decreases decisional regret, "facilitates the grief process and helps the family to cope better afterward" (2). Martinson realized that health professionals often create barriers between the dying child patient and the family, thus creating more angst at the end of life. When the child died, however, in the comfort of the home surrounded by family and loved ones—influenced by effective communication about the goals of care—"death became a positive experience" (3). Death also became a less financially burdensome experience on families. Without proper communication of wishes for the end of life and interventions desired, in-hospital deaths can pose an enormous financial cost. The study showed that average home care cost for children—who had the opportunity to design their own end of life process—cost a mere $945, in comparison to $12,225 for children who died in hospitals. Since 1977 when this study was undertaken, costs have continued to rise, posing significant burden on families of loved ones who are navigating expensive biomedical treatments for terminal illnesses with little autonomy in hospitals.

Eventually, as hospices—uniquely designed for children and emerging adults—sprouted in communities, the hospice movement pivoted to include all patients, regardless of age, in holistic end-of-life care. The Edmarc Hospice for Children was the first hospice established in the United States in 1978 to direct care specifically towards children and adolescents. Founded in Suffolk, Virginia, the Edmarc Hospice aimed to "ease the trauma… and reduce the disabling effects of pediatric illness, loss, and bereavement" both "physically and emotionally" ("About Us"). The hospice currently operates and has grown to serve 70 children and their families daily. Children's Hospice International (CHI) was founded in 1983 by Ann Armstrong-Dailey after realizing that mainstream hospice centers would not accept children and adolescents for palliative and comfort care (Marston). Historically, hospice and palliative care systems do not work as effectively in pediatric populations. Currently, insurance companies dictate that individuals can only enroll in hospice once the patient reaches a prognosis of six months or less (Brody). However, terminal illnesses in childhood and adolescence operate differently, often with the patient "moving in and out of terminal phases" ("About CHI"). This makes prognostication particularly challenging. As such, families are forced to choose between curative and palliative care. Coordinated palliative care, paired with ongoing curative care, at the moment of diagnosis of a chronic illness in childhood and in emerging adulthood has proved effective. After diagnoses like cystic fibrosis, muscular dystrophy, and congenital heart defects, paired palliative and curative treatment promotes ongoing dialogue about goals of care between the medical team, patient, and family.

This challenge of balancing effective palliative care treatment and communication with prognostication was particularly relevant in the case of Mattie Stepanek. Mattie was a young philosopher and poet, living with Dysautonomic Mitochondrial Myopathy—a rare genetic form of muscular dystrophy—that would eventually take his life at the age of 13 in 2004 (Winfrey, *How Mattie Stepanek's Words Inspired Millions*). After his mother, Jeni, unknowingly passed the genetic condition to all four of her children, Mattie outlived his siblings. In the few years that comprised his life, he spoke about the importance of communication in healthcare. In fact, he is considered to be a voice of the pediatric hospice movement that developed at the turn of the 21st century (jeni).

In addition to writing his *New York Times* bestseller book, *Heartsongs*—a compilation of his poetry—Mattie spoke regularly to the mainstream public, often on the Oprah Winfrey and Larry King shows, about his keen understanding of palliative care and passion for discussing the end of life: "Palliative care no longer means helping children die well, it means helping children and their families to live well and then, when the time is certain, to help them die gently" (Marston). As Oprah put it succinctly, Mattie was a "prophet of our time who just happened to be dressed in little boy clothes" (Winfrey, *How Mattie Stepanek's Words Inspired Millions*; Winfrey, *SuperSoul Short*). At his funeral, former President Jimmy Carter eulogized Mattie's loss and described him as "the most extraordinary person whom I have ever known in my life" (Carter). Mattie's exuberance for life, "glass half full" attitude, passion for peace, and open acceptance of his own death illuminated the lives of many that he touched in his remarkably short, yet fulfilling life (Carter).

Twelve years after Mattie died, Oprah visited his mother on her 57th birthday (Winfrey, *SuperSoul Short*). She remarked on his optimism and openness at the end of his life that allowed his mother to continue living on past his death: "Before he died, he challenged me: choose to inhale, do not lay down in the ashes of my life. Do not simply breathe to exist, choose to inhale. And I draw strength from that… One day, we will all die. But on all the other days we will not. And so today let's toast and celebrate to all those other days with gratitude." His spirit towards life and openness towards death signaled a shift in discussing end of life issues directly with terminally ill children.

Mattie's family exemplified ideal pediatric palliative care well before the subspecialty was further developed. In the late 2000s, the medical community realized the importance of engaging in difficult conversations about death and dying with pediatric and adolescent patients directly with support from their families. The NIH funded a $1.6 million grant in pursuit of a standardized curriculum for pediatric palliative care specialists in 2010, which eventually developed into the Education in Palliative and End-of-Life Care (EPEC) curriculum in pediatrics (Marston). To date, this remains the "most comprehensive pediatric palliative care curriculum world-wide" and is "designed to address the needs of children with cancer and other serious illness, their families, and their pediatric clinicians" (Marston). Conversations with pediatric patients and emerging adults living with chronic and terminal illnesses became much less taboo and more commonplace.

Dialogue about Death: Historical Stigma in Childhood and Adolescence. Even with immense strides to improve communication at the end of life with pediatric and emerging adult patients suffering from terminal illness, "talking with [children and] adolescents who have a life-threatening or life-limiting illness is one of the most difficult tasks a health care provider (HCP) can undertake" (Pao and Mahoney 511). Traditional Western medical thought proliferated the norm that end-of-life communication should only occur when life-limiting conditions present at old-age, not amongst younger populations. Historically, common practice dictated a complete avoidance of conversations about death with adolescents and emerging adults. In the 1970s, for example, disclosing a cancer diagnosis to a child “was considered inhumane” (513). Medical professionals did not dare to discuss advance care planning (ACP) and decision-making with terminally ill emerging adult patients.

The drive to be truthful and forthcoming with children and emerging adults is impeded by a deeply rooted Western cultural attitude towards protecting children from undue psychological harm, ultimately causing a complete avoidance of end-of-life conversations. Many physicians and parents falsely believe that children and adolescents “do not understand death and dying or do not have the capacity to make decisions about their own health” (511). Traditionally, this relationship between the patient and physician has been heavily paternalistic—the physician ‘knows best’ model with very little patient autonomy in end-of-life decision-making (Roter and Hall 27-28). In this authoritative power dynamic, the autonomy of the patient is greatly diminished. Dr. Sarah Coombs, a sociologist and educator at the University of Sussex in the United Kingdom, attributes the emergence of helicopter parenting to overly protecting children against conversations about death and dying (Coombs). Childhood and adolescence have traditionally been perceived as a “‘walled garden[s] in which children, being small and weak, are protected from the harshness of the world outside until they become strong and clever enough to cope with it’” (Coombs 286). As such, adults generally fetishize “childhood innocence in order to regulate the knowledge that separates innocence from worldliness” (286). In fact, though death is a “ubiquitous part” of the human experience, talking about death is often compared to taboo conversations about sex, historically “pornographic… a universal fear, denied and invisible and sequestered" (300). This uneasiness is most evident in the context of aversion toward 'death talk' with emerging adults.

As noted earlier, the paradigmatic acceptance of childhood innocence and categorical rejection of death, however, has shifted over the course of time. In their 1997 edition of *Constructing and Reconstructing Childhood,* Drs. Allison James and Alan Prout, both sociologists at University of Sheffield and University of Leeds respectively, explain theories of socialization of children to issues of health and illness. They propose that Western culture shifted from marginalization, "innocence, incompetence, vulnerability and dependency in the 1950s, 1960s, and 1970s," to the "new sociology of childhood paradigm" (James and Prout; Coombs 287). This theory was the transition in the 1980s and 1990s that repositioned "children and childhood within an increasingly agentic, plural and participatory framework" (286). Society radically re-envisioned how to best incorporate the child and adolescent voice into decision-making. Slowly, children and adolescents were "acknowledged as an expert in their own social worlds" (287). Medical decision-making in childhood and emerging adulthood became shared and more autonomous and family-centric, and much less authoritative (Hatano et al.). Moreover, as taboos have shifted "from the margins of society to the mainstream," death has become "the focus of a new permissiveness. Death is in" (Coombs 287). Many attribute this development to increased "media content [that] explicitly relates to death and dying and thus has become a highly visible entity within [young adult] lives" (287). With increased exposure in the media, medical professionals must become more comfortable with providing emerging adults "the opportunity to discuss the subject… if we do not want children to be afraid of death" (Coombs).

Conversations with Terminally & Chronically Ill Emerging Adults: Current Research. The premise of open conversation about death and the end of life is particularly relevant for children and emerging adults living with chronic and terminal illnesses. In understanding how to best navigate end-of-life communication, meaning-making, and decision-making with healthy emerging adults, much insight can be gained through current literature and studies on dialogue with terminally and chronically ill individuals. Given trends in life expectancy in the U.S., generally children outlive their parents and grandparents. And in most cases they do outlive their adult counterparts—in a 2018 report by *The New England Journal of Medicine*, childhood and adolescent (between 1- to 19-years-old) deaths accounted for "less than 2% of all U.S. deaths" (Cunningham et al.). The leading causes of death remain motor vehicle accidents, firearm-related injuries, and malignant neoplasms.

Nevertheless, both the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) have "recognized the significant impact that the sudden death of a young adult has on families and society" ("Cancer in Children and Adolescents"). In fact, recent studies have indicated an increase of accidental deaths, homicides, and suicides of young people ages 10- to 19-years-old. Between 1999 and 2013, the total death rate for the aforementioned population decreased 33%, but then skyrocketed another 12% between 2013 and 2016 (Howard). The World Health Organization reports that of the 1.1 million adolescents ages 10-19 that died in 2016, over 135,000 resulted from car-related accidents, the leading cause of death for emerging adults globally ("Adolescents: Health Risks and Solutions"). Suicides, the second leading cause of death for emerging adults, have increased significantly since 2007 (Howard). Often, such events are coupled with emotionally heavy and psychologically challenging decision-making, often in the context of intensive care. In the aftermath of a sudden death, families and friends are left grieving and wondering what the emerging adult would have preferred at the end of life.

Emerging adults are also not immune to terminal illness. Though there have been breakthroughs in cancer treatment in recent years, pediatric cancer remains the third leading cause of death amongst the aforementioned population—representing “9% of overall deaths among children and adolescents” (Cunningham et al.). Cancer affected an estimated 15,590 children and adolescents (0-19 years of age) in the U.S. in 2018, according to the National Cancer Institute. According to recent statistics released by the CDC, each year more than 11,000 adolescents and young adults (15-34 years of age) die from chronic illnesses, including malignant cancers, heart disease, and HIV. And the number of emerging adults living with chronic illness is steadily rising (Wiener et al. 898; Zadeh et al.).

Emerging adulthood is the optimal time for beginning what is usually a life-long process of forming romantic and personal relationships; engaging in professional development and career decisions; and experiencing academic growth in college. Life-limiting conditions that present in emerging adulthood threaten typical development and the occurrences of major life events during the transition to adulthood. Emerging adults facing the end of life are not able to achieve their aspirations in the same way as other peers (Pao and Mahoney). Oftentimes, life-threatening illness “challenges healthy adolescent development by compromising independence… interfering with school and social interactions, and potentially causing physical and emotional changes, arresting further development” (Wiener et al. 898). Diagnosis of a terminal or life-limiting illness is often compounded by depersonalized interactions with the medical team; increased physician paternalism and decreased patient autonomy; intensely industrialized and commercialized hospital settings; and complicated bio-medicalized communication (Lyckholm and Kreutzer).

Yet, even with increased familiarity and prevalence of palliative care, emerging adults are not provided with constructive outlets to discuss their frustrations and fears. In fact, palliative care and psychosocial oncology researchers have concluded that chronically sick children and emerging adults are innately aware of their health situation, and many “conceal knowledge of their impending death from their parents at the same time the parents were attempting to suppress any discussion about the child’s serious illness in the ‘maintenance of mutual pretense’” (Pao and Mahoney 513). In a study of emerging adults who were diagnosed with a life-limiting condition before 17-years-old—and died before 25 years of age—researchers identified themes in the progressive conversation between parents their terminally ill kin. Most notably, the overall theme was that communication occurred “on the child’s own initiative” (Jalmsell et al. 112). Generally, the children and emerging adults were well aware of their medical condition, and the “child’s own awareness of his or her impending death was what triggered the conversation” with the parents (115).

Advance Care Planning after Terminal Diagnosis in Emerging Adulthood. The avoidance of such conversations about death, paired with lack of physician communications training, further the inability to talk about end-of-life planning tools that are the crux of decision-making. ACP encompasses both advance directives and power of attorney in end-of-life decision-making. Generally, ACP consists of four measures: 1) “identification of the decision-makers, including the adolescent,” 2) “clarification of the patients’ and parents’ understanding of the illness and prognosis,” 3) “establishment of care goals as curative, uncertain, or comfort care,” and 4) “joint decision-making regarding use or nonuse of life-sustaining interventions such as mechanical ventilation, intravenous hydration, or phase I chemotherapy” (Pao and Mahoney 520). Advance

Figure 1: Cycle of End-of-Life Conversations and Decision-Making (Pao and Mahoney 512)

directives (AD) and durable power of attorney for healthcare (DPOAH) are two examples of medical/legal tools that provide structure to ACP. They are often utilized on the patient's deathbed, but can be completed and changed at any point during the lifetime (see fig. 1). ADs are the legal documents that outline wishes about one's care at the end of life. Inherent in its name, the goal is to provide medical professionals and family members with a tangible plan in advance of death. A DPOAH is a legally appointed individual to make surrogate decisions in the event that the patient is unable, thus avoiding confusion. Both tools together provide families with guidelines for an individual's desires at the end of life.

Inadequate and late conversations about ACP have been shown to perpetuate a sense of isolation, fear, and anxiety for the emerging adult patient. Many "health care workers [are] not well-versed in the spectrum of normal social, emotional, cognitive, and language skills in adolescent development," ultimately inhibiting healthy aforementioned discussion from occurring (Pao and Mahoney 516). Oftentimes, professionals are concerned that ACP and the related documents will destroy hope, but studies show emerging adults "appreciate open and honest discussion" (Wiener et al. 902). In fact, ACP has been shown to "alleviate anxiety and distress by allowing adolescents the ability to express their preferences and helping parents and [health care provider] make informed decisions while potentially improving the adolescent's quality of life" (Pao and Mahoney 526). As such, providers must be given outlets to better process their "personal feelings about death in order to be effective in providing support to adolescents who are facing their own impending death" (514). Both informal and formal introspection practices, in addition to better communications training, are effective in interacting with emerging adult patients at the end of life, and creating a shared language and understanding between patient and provider. Ultimately, in addressing the wishes of emerging adults before the end of life, better care can be provided to lessen the psychosocial-emotional trauma for the family, patient, and medical team. Direct conversations between medical team and patient have become a standard of care in Western medicine.

Gaps in Care: Lack of Provider Communications Training. Though conversations about end-of-life decision-making, with both healthy and terminally ill emerging adults, have proved crucial in improving the holistic well-being of the patient and family, healthcare professionals lack communications training to facilitate such dialogue. Given the stigmatized history of death in Western medicine, healthcare professionals—including those working in pediatric palliative care settings—lack proper education about palliative care. With a growing societal interest in death and dying; concern about "high cost of dying"; increasing focus on pain management; role of medicine in caring versus curing; and debates on physician-assisted suicide and euthanasia, death is a hot topic in the medical community (Billings 733). However, historically that has not always been the case. In fact, in a 1997 paper, they reported "no clear standards… [that] exist for undergraduate or graduate training in palliative care in the United States, or for clinical practice in the hospital, nursing home, or hospice, except in the area of pain management" (733).

Formal education about end-of-life care did enter medical school curricula in the late 1960s; however, only 3% of medical school student presidents found the terminal care education to be "very effective" given the time constraints within the curriculum (Billings 734). There exists a lack of adequate teaching in medical training, leaving physicians feeling ill prepared to engage in conversations about death with patients, and many yearn for more training. The authors explain that many medical educators criticize the historical avoidance of 'death talk' within undergraduate medical curricula. However, they propose that medical education should ideally "encourage students to develop positive feelings about dying patients and their families and about the role of the physician in terminal care" (735). Furthermore, "academic clinical settings tend to have a negative effect" on medical students; thus, particular attention is required to provide a positive experience "in caring for the terminally ill" within the training curriculum (736). In a more recent meta-analysis of literature published between 2005-2015, researchers noted that though there was an increased appreciation of palliative care education and training to engage in end-of-life conversations within undergraduate medical curricula, “too often, the palliative care curriculum is viewed as ‘optional’. Therefore, students may judge the content as less important. The omission or minimization of palliative care content on standardized exams reinforces the view that palliative care knowledge and skills are not foundational and thus less necessary to master” (Head et al. 111).

Linguistic analyses of interactions between physicians and patients discussing end-of-life planning tools confirm the lack of attention and time dedicated to difficult conversations. In a 1998 study published by Dr. James Tulsky, the Chair of Psychosocial Oncology and Palliative Care at Dana-Farber, he speaks to the inadequate physician training and subsequent lack of comfort primary care physicians feel when engaging in conversations about end of life (Tulsky). In an average physician visit, a discussion about ADs with a patient lasts a mere 5.6 minutes (Tulsky 443). The physician speaks for a median of 3.9 minutes and the patient for 1.7 minutes (443). Physician training is clearly needed to facilitate and constructive end-of-life conversations within the clinical setting.

In the context of pediatric and adolescent end-of-life conversations, communications training is particularly important as the care is generally family-centered, adding a layer of complexity. A study at the School of Nursing, Midwifery, and Paramedicine at the University of the Sunshine Coast in Australia discovered that there is lack of support for pediatric professionals and a hesitancy to engage in end-of-life conversations (Henderson et al.). Physicians who regularly interact with emerging adults must be specially trained to work with that population; age-appropriate conversation skills are critical to enable the patient’s understanding. In response to this failure of education, many studies point to the necessity of additional skills-based physician training for navigating difficult conversations to ultimately "emphasize humanistic attitudes" in end-of-life care (Billings 736). As another report noted, in "employing these skills, students will see patients respond with gratitude and will be rewarded, encouraged, and even challenged by a sense of enhanced clinical competence and mastery, rather than retreating from or even scorning situations that otherwise might seem painful, confusing, and frustrating" (737).

In describing their study at Children's Hospital of Philadelphia, researchers elaborate on the role physicians play in facilitating conversations with pediatric oncology patients. Parents appreciate "timely, honest, and nonconflicting information" to reduce distrust between the medical team and family (Odeniyi et al. 909). In fact, conversations about healthcare decision-making with chronically ill children and emerging adults are recommended as soon "as they are developmentally and emotionally ready" by the American Academy of Pediatrics (AAP), the World Health Organization (WHO), and the Institute of Medicine (Pao and Mahoney 511; Sanders and Robinson; Wiener et al. 898). Moreover, when the care the physicians believe is most appropriate does not align with the desires of the family, the "levels of stress and dissatisfaction" and feelings of moral distress increase (Odeniyi et al. 911). Transparent conversations have been shown to empower patients and their families in anticipation of death.

Various initiatives have been spearheaded in recent years to improve physician and medical professional communication in the workplace and clinical settings, particularly regarding palliative care and end-of-life situations. VitalTalk, for example, was founded in 2012 to better arm clinicians with communication skills for the bedside. VitalTalk partners with institutions and provides clinicians with resources and courses to improve healthcare communication with patients suffering from serious illness. The organization utilizes and recruits expert faculty from institutions around the globe to "practice what they teach" and educate other budding clinicians on how to best capitalize on their interpersonal skills ("About Us"). VitalTalk also provides communication guides for healthcare professionals to use during times of crisis, most recently for the novel coronavirus outbreak (COVID-19). The guide published on March 18, 2020 is available in multiple languages and guides practitioners through screening and triaging patients; admitting to the ICU; counseling and emotional support; deciding goals of care and code status; resourcing and rationing; anticipating end-of-life decision-making; and grieving and bereavement support (Arnold et al.). Similarly, Ariadne Labs, a joint venture between Brigham and Women's Hospital and Harvard's T.H. Chan School of Public Health founded by Dr. Atul Gawande, produced a Serious Illness Conversation Guide to walk physicians through conversations about prognosis and goals of care (Bernacki and Ariadne Labs). Since 2012, this guide has been refined, shared publicly, and utilized by healthcare professionals to better streamline effective communication at the bedside for patients with serious, life-limiting illnesses ("Serious Illness Care").

Parental Processing, Decisional Regret, & Bereavement: Insight into Decision-Making & Ethics. Conversations about death also assist in familial bereavement practices. Oftentimes, end-of-life practices serve those who will continue living beyond the loved one who dies. In the context of terminally ill emerging adults, parents "face the possibility of surviving their own child" (Jalmsell et al. 111). It is understandable that "being told that one's child is likely to die is undoubtedly among the worst fears of any parent" and has been "described as one of the most stressful life-events possible" (111). Accordingly, many parents live with the burden of major care decisions. In terms of parental decisional regret, one study showed 27% of parents who did not talk to their child about death regretted not doing so (Pao and Mahoney 514). And ultimately, families are forced to "live with the consequences of their decisions forever" (Odeniyi et al.

913). Therefore, open communication undergirds the efficacy of end-of-life communication. Alternatively, poor communication "has been seen as a factor that increases distress for both the sick child and his or her parents" (Jalmsell et al. 111). It is evident that "withholding information about an adolescent's medical status can cause them to suspect that they are more seriously ill, increase sibling suffering, strain the parental relationship, and jeopardize trust" (Pao and Mahoney 513).

To encourage communication with pediatric and emerging adult patients, medical ethicists have advocated for enhanced patient inclusion in medical decision-making through hospital policies and institutional review boards. The Belmont report—published in 1976 to identify "the basic ethical principles that should underlie the conduct of biomedical and behavioral research involving human subjects—proposed three key ethical principles of medical care and research: respect for persons, beneficence, and justice. The foremost principle emphasized "the requirement to acknowledge [individual] autonomy and the requirement to protect those with diminished autonomy" (Kon 1806). The latter of the two has been justified to exclude children from decision-making, particularly in the context of serious illness, as they are not considered to be cognitively mature. However, as cognitive development has become more clearly understood, children, adolescents, and emerging adults should be "seen as individuals with emerging autonomy and progressively increasing cognitive and emotional development" (1807). In fact, "by the time children reach adolescence, they are capable of having mature discussions and processing information with a level of thinking similar to an adult" (Berger 12).

With an increasing awareness of cognitive capacity in adolescent patients, pediatricians and internists in the U.S. defer to the assent of the patient to continue with certain medical treatments. Children and adolescents are not permitted to consent to medical procedures and treatment until they are 18 years old; however, assent, which essentially allows the child to agree to the treatment, can be obtained in pediatric populations. The patient can also dissent. Assent allows adolescents and emerging adults, who are still legally minors, to take an active role in the communication regarding their care. While assent or dissent provides the patient with a voice as minors, the medical team defers to the parents for a final healthcare decision, unless legal emancipation procedures are pursued (Kon; "Children's Assent"). Though procedures and diagnoses may be worded differently to fit their understanding, the child or adolescent is presented with data to make an informed decision for their care and is encouraged to ask questions (Pao and Mahoney 515).

Truth-Telling in Decision-Making: A Global Standard of Care? It is important to note, however, that while Western culture has slowly come to prioritize honesty, directness, assent, and "open communication about death," it is not necessarily the globally practiced norm (Hatano et al. 494). In Japan and other Asian cultures, for example, "truth telling," with regard to terminal illness diagnoses, is not practiced in pediatrics. Parents and physicians often choose to protect children and emerging adults from "bad news" (491). Including children and adolescents in conversations about their diagnosis may "take away the child's hope" (493). As opposed to Western culture, "a child is not regarded as an individual, but as a family member for whom the parents are responsible" (493). These beliefs have permeated Western medical thought as well; many parents still believe that "talking about end-of-life will make it happen (magical thinking) and that it will increase rates of depression, threaten patients' and families' hope, and reduce rates of survival" (Pao and Mahoney 515). And despite the lack of dialogue with terminally ill emerging adults and the previously cited statistics, end-of-life planning is not perceived as necessary for healthy emerging adults; "In the United States, less than one third of adults have an [advance care planning] document" (Sanders and Robinson 330). The reluctance to speak with emerging adults about their terminal diagnoses ultimately harkens back to age-old theories about welcoming death at one's doorstep too soon. These alarming trends signify a continued gap in public knowledge about end-of-life planning due to entrenched stigma and fear.

CHAPTER THREE:

DEATH CONCEPTUALIZATION IN CHILD & ADOLESCENT COGNITIVE DEVELOPMENT

Pediatric Psychological Development & Stages of Death Awareness. Psychological and neurological development in childhood and adolescence sheds further light on potential entry points for sustained palliative care education amongst healthy emerging adults. The literature indicates that terminally and chronically ill children, adolescents, and emerging adults are aware of their own finitude and impending death. Understanding how this conceptualization comes to fruition may provide insight into potential ways of engaging healthy emerging adults in conversations about death. Psychological development and associated theories help explain the crucial transition from childhood to more mature thinking in adolescence and emerging adulthood. An understanding of childhood and adolescent psychological development should significantly inform the approach to palliative care in an undergraduate setting.

An individual's understanding of death is generally grounded in four well-documented concepts. The first is universality, also known as applicability and inevitability, which is the acceptance and acknowledgement that "death must happen to all living things eventually" (Slaughter and Griffiths 526). The second is nonfunctionality, which is the knowledge that "death is characterized by bodily processes ceasing to function." The third is causation, which is the understanding of what causes death to happen—the breakdown of bodily function. And the fourth is irreversibility, or finality, which is the "recognition that the dead cannot come back to life"—that death of an individual is permanent. The sequence of fully understanding these death-related concepts has been studied and shown to occur between five and ten years of age.

Parental responses play a large role in assisting a child to better understand death and learn how to cope with trauma, grief, and bereavement. Though it is still debated, Dr. Maria

Nagy, a child psychologist, pioneered a study in 1948 to theorize childhood stages of understanding death. She examined 378 children in Budapest, Hungary just before World War II (Corr et al. 328). Her study asked groupings of children—3-5-years-old, 5-9-years-old, and 9-10-years-old—to articulate and illustrate what "comes into your mind about death" (328). Nagy characterized the first stage, between 3-5-years-old, as the child simply seeing "death as a mere departure from a place…" (Willis 222). For example, a friend has moved away and gone somewhere else. The definitiveness and finality of death is not fully understood in this stage. Next, Nagy explains that children from 5-9-years-old begin to understand that death is final, but believe they can avoid death—the personification of death allows children to treat it at a distance, that it is not relevant to their existence and not universal. During the final stage, between 9-10-years-old, Nagy proposes that children understand death as permanent, inevitable, and realize their own potential to die.

As theorists, developmental psychologists, physicians, and philosophers have further delved into cognitive development and perceptions of death, the stages have extended into adolescence and emerging adulthood. Psychologist Jean Piaget studied the evolution of the mind and the child's understanding of death. He proposed similar stages to that of Nagy: sensorimotor (0-2 years); preoperational (2-7 years); concrete operations (7-12 years); and formal operations (13 years and up) (Wadsworth; Willis). At first, behavior and response to death begins with mirroring parental emotions. Even at young ages when children cannot grasp the complexity of death itself, they may feel grief and sadness after a friend or family member passes. As children grow into adolescents in their teenage years, they grow inherently curious about death. In talking about death in childhood and adolescence, euphemisms—like "gone on," "passed away," "in a better place," "gone to sleep" and "left us"—are too abstract and hold little educational meaning

(225). In fact, euphemisms highlight discomfort and fear, and further deny the reality of death (Hughes et al.). As such, Piaget proposes using a concrete terminology and approach to teaching children and adolescents about death. This assists during the last of the stages of development, as he postulates—the transition point to where death is understood to be part of the human experience, but appropriately perceived to be far off and at the "end of a long life."

Contextualizing Death: Emotional Maturation in Adolescence & Emerging Adulthood. The typical healthy adolescent and emerging adult relationship with death, as mentioned earlier, is largely undertheorized and understudied. Cognitive development and emotional maturation, however, can illuminate the self-perception of death and associated behaviors. Emerging adults are at a particular stage of development wherein they are not fully prepared to confront difficult complexities and inherent ambiguities of death. Adolescent development, often defined as individuals in the "second decade of life and sometimes beyond," is accompanied by "independence from parents/family" and by purposeful "abating dependence on their parents" (Dehlin and Reg 14). Puberty not only causes physical maturation, but so too cognitive development and "strong implications for social and emotional growth" (Noppe and Noppe 147).

Pragmatically speaking, the course of development and growth are also accompanied by the death of others previously present in the life of an adolescent and emerging adult. Emerging adulthood is often a period where individuals may lose a parent or grandparent. In fact, "in the United States, it is estimated that more than 2 million children and adolescents younger than 18 years have experienced a parental death" (Dehlin and Reg 13). In a 1979 empirical study by Dr. Patricia Ewalt, the dean of University of Hawaii School of Social Work, she assesses the psychosocial impact of deaths on adolescents. Shockingly, in a survey of over 1,000 high school students, 90% of respondents reported that a "relative or someone else that they had cared about, including a close friend, had died" (Noppe and Noppe 156). Recent studies have confirmed that "at least one-quarter of [undergraduate] students are either grieving over a deceased family member or friend" (156).

Even in the context of death during emerging adulthood, however, conceptualizing one's *own* death, and even those of their loved ones, is still inconceivable and unrealistic. The wealth of literature about grief and bereavement responses gives a glimpse into the perspective of an emerging adult in the aftermath of death. Though maturing adults generally share a more abstract, universal, and comprehensive conception of death, death as a concept can shake the emerging adult's and "adolescent's sense of fairness and justice" (157). As such, many studies have observed a resulting increase in participation of death-defying activities in adolescence and emerging adulthood. Consequentially, this premise elucidates both "fearless notions of immortality, and unhealthy patterns of behaviors on the one hand, and an increasing awareness of death, a developing sense of rationality, and the unfolding of life's possibilities on the other hand" (146).

The study of typical neurological development in emerging adulthood further aids in understanding decision-making and death perception. With the onset of puberty, the frontal lobe begins to further develop into emerging adulthood. The frontal lobe and prefrontal cortex development are associated with higher-level decision-making and emotional thinking, and enhanced social behavior. As significant frontal lobe growth begins during adolescence, it is implicated in risky and unwise decision-making, and a "low perceived vulnerability to harm" (Duke et al. 224). Consequentially, emerging adults often grapple with realizing their own mortality as part of typical development. The fear of mortality often drives adolescents to "test the limits of life by tempting fate with activities that only seem to beg for death… the closer to the edge that one goes, the greater the thrill of defeating death" (Noppe and Noppe 152). Emerging adults often justify these risk-taking behaviors with the "nothing can happen to me" immortal mentality (153). Most literally, this fear—and subsequent temptation—is presumed to be an associated response to a "critical transition that marks the death of childhood and the beginnings of adult developmental stages" (154).

Early Perceived Death Amongst Healthy Emerging Adults. High levels of death anxiety, evident in emerging adult populations, lead to perceived feelings of premature death (Noppe and Noppe 154). In fact, statistics show that, though "in the setting of relatively accurate perceptions of probabilities for life events," teens in the U.S. regularly "overestimate the risk of dying early" (Duke et al. 225). In a 2008 study on unrealistic fatalism in individuals ages 14- to 22-years-old, "almost one in 15 young people [reported] perceived high risk of death by age 30 years" (225). The National Longitudinal Study of Adolescent Health confirmed this, finding that "nearly one in seven youth perceive a high risk of death before the age of 35 years." Premature death perception has been correlated with learned helplessness, maladjustment, and depression in emerging adults. More shocking, however, is that early death perception "predicts poor health and productivity in young adulthood" and can endanger cognitive and emotional development (230).

The transition from more absolutist perceptions about death held during childhood and adolescence to a multifaceted perspective in adulthood manifests over the course of the lifetime, through "the myriad life experiences… expanded interactions, work settings, and family relationships" (Noppe and Noppe 151). However, the shift that "culminates in reducing risk-taking behavior" and ends with a "coherent world view" is lengthy (151). Dr. David Elkind, an American child psychologist, proposed that "the natural optimism of adolescents in conjunction with their egocentric perspectives" drives a "strong underlying tension between embracing life and knowledge of death" (153). To enhance the relationship of healthy emerging adults with death, especially given that current research continues to illuminate increased anxiety around existential questions, solutions to improve optimism and decrease perceived feelings of premature death are crucial in bettering the mental health of emerging adults. Rather than avoiding death—as historically and falsely believed to be advantageous—discussing the harrowing topic directly has been shown to decrease feelings of extreme loneliness and alienation. Creating a space in which healthy dialogue about death occurs can not only lead to better control of emotions about premature death, but so too restore order for which emerging adults are searching during the transition from childhood to adulthood (Dehlin and Reg 20-21).

Healthy conversations about death during typical adolescent development, and subsequent stages of early adulthood, are crucial for arming the next generation with practical and philosophical skills in decision-making. As parents and grandparents age alongside their young adult kin, emerging adults are often responsible for their elders' medical decision-making, especially in the context of parental terminal and chronic illness. Emerging adults grow into the role of caretakers of their parents. Prior conversation about AD and DPOAH, amongst other tools that palliative care provides, can enhance the decision-making capacity of an emerging adult. Ultimately, typical feelings of guilt, anxiety, depression, worry, and grief may be lessened. This novel concept of engaging in dialogue counteracts the premise of aversion to death amongst young people "in order to protect themselves" (Dehlin and Reg 14). Thus, research clearly points to the importance of dialoguing about death with emerging adults to "identify youth who are doing well," assist with "achieving goals," and identify those "who may require further intervention… [and] are struggling emotionally and/or socially" (Duke et al. 233).

CHAPTER FOUR:

SHIFTING PERSPECTIVES: TALKING DEATH WITH HEALTHY EMERGING ADULTS

As evidenced by the wealth of literature on the history of palliative care within adult and pediatric populations; the shifting emphasis to include families and terminally ill emerging adults in end-of-life planning; enhanced provider communications training; psychological conceptualizations of death in emerging adulthood, and the newly established standards of care in Western medicine, it is clear that conversations about death and dying—philosophically and practically—are important for healthy development. Though not much literature has been published on engaging healthy emerging adults in ACP and ‘death talk,’ the studies and tools that do exist confirm that it does aid in psychological development and in lessening the impact of perceived early death.

Healthy Emerging Adults & Advance Care Planning. To best develop an undergraduate palliative care curriculum, insight can be gained by understanding current attempts to implement advance care planning in settings with healthy emerging adults. Dr. Jennifer Tripken, an educator, and Dr. Cathy Elrod, a physical therapist researcher, published a mixed-methods study to better investigate the need for enhanced interventions and discussion with healthy young adult populations about death and dying. Their 2018 paper, “Young Adults’ Perspectives on Advance Care Planning,” hypothesized that the goal of early conversation about ACP helps “create a shared understanding about a person’s values and care preferences” and “improve[s] the quality of end-of-life care and reduce[s] caregiver and health-care proxy stress” (Tripken and Elrod 627). Similarly, they claimed that engaging in such conversation prior to the onset of chronic illness decreases stress and increases awareness of end-of-life planning long before death occurs. In fact, undergraduates were much less familiar with palliative care terminology, approach, and language in comparison to older peers. In accordance with national data on ACP, only 36.5% of young adults had discussed end-of-life planning and wishes with their families (631). Dr. Dio Kavalieratos, the Director of Research at the Emory Palliative Care Center, found similar results in his 2007 study, “Knowledge, attitudes, and preferences of healthy young adults regarding advance care planning: a focus group study of university students in Pittsburgh, USA.” Given the WHO and AAP standard for engaging adolescents and young adults in healthcare decision-making, as cited earlier, he proposed the importance of discussing ACP with university students age 18- to 30-years-old (Kavalieratos et al. 2). This novel study revealed that “relatively few young adults fully understand ACP concepts” and “all young adults in [their] sample desired to learn more about ACP” (6). Proposed educational interventions may help improve ACP knowledge and understanding.

Adapting Current Tools: Interventions with Terminally Ill Emerging Adults. To increase awareness and decrease stigma surrounding death and dying, particularly amongst young emerging adults, several interventions have been developed. Many of these tools were initially used amongst terminally ill patients, and were expanded to innovatively and proactively engage communities in conversations that matter. Discussing end-of-life care amongst terminally ill emerging adults was never commonplace and often was overly intense and difficult. Even at the turn of the century with an increased awareness of end-of-life issues, discussions were largely avoided. In a 2008 study published by Dr. Lori Wiener, the Director of the Psychosocial Support and Research Program at the National Cancer Institute, *Five Wishes* emerged as a successful tool for facilitating end-of-life conversations with adolescents and young adults. The guide included “issues of comfort, future planning, and spiritually along with choosing a durable power of attorney [for healthcare] and specific life support options.” *Five Wishes* was amongst the first iterations of ACP to be used with emerging adults, and was received well by patients and families. With the feedback they received about *Five Wishes*, Wiener and her team at the NIH developed *My Thoughts, My Wishes, My Voice* (MTMWMV). MTMWMV was developed as a guide to help adolescents and young adults express "their values, beliefs, and preferences" (Wiener et al. 898). The tool was piloted with patients (ages 16-28) with HIV-1 and metastatic/recurring cancer to analyze the efficacy of the questions asked to ultimately build the best planning guide for adolescent and young adult patients.

Documents like *MTMWMV* and *Five Wishes*, amongst others, have proved effective in clinical practice. In a 2015 *New York Times* article, "Teenagers Face Early Death, on Their Terms," the author features AshLeigh McHale, a 17-year-old melanoma patient (Jan Hoffman). Forced to make decisions about her end-of-life care as the disease metastasized to her vital organs, she found strength with the help of family and the medical team at the NIH, to die at home on her request. Amidst extreme grief from her parents and family, she had the opportunity to write her own instructions and lay out her plans on her own terms. AshLeigh used *Voicing My CHOiCES*, another adaptation of *MTMWMV* and *Five Wishes,* to guide her decision-making for the end of life. *Voicing My CHOiCES* is a 'first-of-its-kind' planning guide for the end of life "created for—and largely by—adolescents and young adult patients" in collaboration with Wiener and Dr. Maryland Pao, the Clinical Director of the National Institute of Mental Health. Two years after it was released by Aging With Dignity in 2013, over 20,000 copies had been ordered to over 70 different medical centers, and has since been translated since into multiple languages (Jan Hoffman). Emerging adults who utilize this guide are encouraged to answer questions like "what gives you strength or joy?" and "who do you wish to forgive?" Other parts of the guide focus on remembrance—How one wants to be remembered: buried, cremated, open casket, celebration of life, etc.? Who inherits one's cherished memorabilia? What does one want their friends and family to know about them? The guide also helps emerging adults vocalize clearly how they would like to be supported and comforted, including age-appropriate and accessible definitions surrounding issues of life support. At the conclusion of the guide, the emerging adult patient has the opportunity to write messages and letters to loved ones to express their inner "voice" ("Voicing My CHOiCES"). Ultimately, the document is malleable and can be a source of hope and control for patients battling terminal diagnoses, and perhaps proactively in populations of healthy emerging adults.

AshLeigh's narrative of end-of-life planning was aligned with a 2015 national study—"Dying in America"—by the Committee on Approaching Death, as part of the Institute of Medicine. Researchers found that "the great majority of the adolescents" with chronic conditions want to discuss their diagnoses (U.S. Institute of Medicine 3-21). The report goes on to assert that 90% of the emerging adult patients with AIDS surveyed "wanted to talk about end-of-life issues before entering the dying phase, including 48 percent who thought the best timing for end-of-life decisions was before getting sick and another 24 percent who wanted to have conversations throughout the illness trajectory: before getting sick, when first diagnosed, when first sick, and when dying" (3-21). While parents may want to restrict the conversation from occurring too early while the emerging adult's health "relatively stable," anticipatory conversations and ACP is important prior to the onset of debilitating symptoms (3-21). As one student contributor—Pamela Hinds at Children's National Hospital and George Washington University—on the committee explained, "adolescents are competent enough to discuss their end-of-life preferences… studies show they prefer to be involved and have not been harmed by any such involvement" (Jan Hoffman). This supports an important finding—that aforementioned current tools could be used within populations of healthy emerging adults to spark crucial dialogue about death.

Innovative Gaming: Engaging Healthy Individuals in Death Talk. The ACP guides traditionally used with terminally ill emerging adults have recently been adapted into community activities and games, making the questions accessible to healthy individuals. Common Practice, for example, is a gaming company that collaborates with medical professionals and researchers to design niche conversation games aimed to encourage healthy conversation amongst families, friends, and strangers about “what matters most” (“Research: *Hello*”). Their staple game *Hello* was originally preceded by *My Gift of Grace,* a community card game for individuals 13-years-old and older to talk personally about end-of-life issues. Dr. Lauren Jodi Van Scoy, a pulmonary and critical care physician at Penn State University College of Medicine, investigated the efficacy of *My Gift of Grace* in her 2016 study published in the *Journal of Palliative Medicine*. ACP, as explained by Van Scoy, is all encompassing, and includes early community interventions to destigmatize palliative care. When it comes to practicality of care, Van Scoy reflects that planning does not happen as often as it should in the U.S.. In fact, “over 75% of adults do not have discussions with family members about their [end-of-life] wishes” (Lauren Jodi Van Scoy et al. 661). However, conversations had through the game were reported to be “satisfying, realistic, of high self-rated conversation quality with no significant negative effects on emotional state” and ultimately “fun and enjoyable” (663-664). This game, as shown by the study, proposes that “playing the conversation game… would result in satisfying and realistic conversations about [end-of-life] issues” (661). Since its development, it has been used in various settings, in community members, at the family dinner table, amongst spiritual leaders and hospital chaplains, and with physicians and trainees. A friendly and casual gaming environment—even about challenging topics—provides a safe and playful environment for fruitful and candid conversation.

Understanding Communication Amongst the Emory Undergraduate Population: A Feasibility Study. To corroborate the theories of engaging healthy undergraduates in end-of-life planning, a feasibility study was conducted as part of a final project for Dr. Susan Tamasi's Health Communication course in Spring 2019. The study aimed to better understand familiarity of healthy college-age emerging adults with end-of-life-related tools and comfort level in discussing death and dying. The survey was posted to two moderated Emory University Facebook groups. The survey was also sent to selected individuals and distributed to additional participants at the request of the surveyor. Responses were collected, resulting in 67 total participants (n=67), between 18-23-years-old.

Institutional Review Board Approval. IRB certification was not required for the Health Communication course, as per Tamasi's instruction. The information collected was deidentified and collected no personal health information. Retroactive approval to include the data was granted under the IRB protocol submitted for the current honors thesis research, evaluating the efficacy of the piloted IDS 205W undergraduate curriculum in palliative care. The details of this IRB certification (IRB00116952) are outlined in Chapter 6.

Methodology & Study Design. Those who agreed to participate were asked a series of questions in three categories: 1) Demographic Information; 2) Familiarity with End-of-Life Communication Tools; and 3) Comfort Discussing the End of Life (see Appendix A). Demographic information included age, status as undergraduate student, institution of study, and major. Familiarity covered specific end-of-life tools often consulted in the context of medical decision-making for emerging adults with life-limiting conditions. Questions surveyed familiarity with AD, DPOAH/health care proxy, and do-not-resuscitate (DNR) orders. Respondents were asked about conversations with healthcare providers, family members, and academic touchpoints, and prior dialogue regarding the aforementioned tools. Additionally, participants were asked if they had previously completed the tool themselves (barring the DNR order, as DNR orders are generally used in the context of critically ill individuals). With the assumption that individuals completing the survey were healthy emerging adults, they were not asked if they had previously completed a DNR order.

The third section pertained to comfort discussing the end of life. Participants were asked if they had spoken to both their mother and father about their parents' wishes for the end of life. They were also asked if their parents/guardians had spoken with them directly about their individual wishes for the end of life. Participants were asked about current comfort discussing end of life. Finally, participants were asked if end-of-life education and dialogue should be included in high school and post-secondary education institutions, respectively.

Limitations. It is important to name one significant limitation of the feasibility study: the survey was collected with an assumption that the participants were healthy. With the knowledge that emerging adults are prone to the same chronic conditions as any individual regardless of age, the subsequent survey for the thesis IRB-approved study included a question evaluating whether or not a student respondent was diagnosed with a chronic or terminal illness. As mentioned prior, emerging adults who suffer from life-limiting conditions often have contact with palliative care and intensive care physicians. Having such close interactions with hospital specialists increases the chance of familiarity with end-of-life-related tools and terminology. Additionally, though participants were asked in the feasibility study if they learned about certain tools in academic settings, participants were not explicitly asked if they were 'pre-health.' Pre-health and nursing students may also know more medical terminology than business or liberal arts students, influencing their responses. We did not account for this variables in collection and analysis of the data. All responses were anonymous.

Lastly, it is critical to acknowledge the potential for response bias in the feasibility study. The survey was distributed in readily accessible Facebook groups oriented for Emory students, many of whom are fellow classmates and similar in age. It is important to note that socioeconomic and race discrepancies were not taken into account in the demographics. This participant pool is not representative of a national or global perspective on end-of-life communication amongst healthy adolescents and young adults; thus, no causational blanket claims can be determined by the results.

Results & Findings **(Feasibility Study, see Appendix B).** Of the 66 respondents counted for analysis, 17% were first-year students, 10% were second-year students, 50% were third-year students, 20% were fourth-year students, and 3% were graduate students (Graph 2). Majors were mixed—participants study in various fields, including biology, anthropology, economics, business, philosophy, psychology, undeclared, and more.

As for familiarity of various end-of-life communication tools (see Appendix A, Section 2), results were mixed. 58% of students had no prior knowledge of ADs (Graph 3). 82% of respondents reported never speaking with their parents/legal guardians about ADs (Graph 5). Only 18% of students had previously learned about ADs in academic courses (Graph 6). A mere 8% of students previously completed an AD (Graph 7). As for DPOAH, 53% of students responded having prior knowledge of the tool (Graph 8). Similar to ADs, 82% of respondents reported never speaking with their parents/legal guardians about DPOAHs (Graph 10). 17% of students had previously learned about DPOAHs in an academic course (Graph 11). Only 11% of students reported having previously designated a DPOAH (Graph 12). 100% of respondents reported never speaking to a primary care physician about both the AD and DPOAH (Graph 4 & Graph 9). On the other hand, 91% of students reported previous knowledge and familiarity with a DNR order (Graph 13).

Comfort discussing the end of life was also gauged in Section 3 of the feasibility survey (see Appendix A). Respondents were asked on a Likert scale about comfort discussing death. Looking at trends between the graphs, respondents reported similar difficulty speaking with family members and friends (Graphs 14 & 15). Respondents reported a slightly increased ease of raising and engaging in conversation with friends about death and dying, rather than family members, 51.6% versus 50% respectively (Graphs 14 & 15). Though a slight preference exists to discussing end-of-life issues amongst friends, a larger sample size is necessary to make proper inferences.

Participants were also asked about conversations with parents about wishes at the end of life. 62% of respondents reported having no prior conversations with their mothers about their wishes for the end of life (Graph 16). Similarly, 64% of participants reported having no prior conversations with their fathers about their wishes for the end of life (Graph 17). 82% of legal guardians had never spoken to their children about the respondent's wishes (Graph 18). When asked about comfort, 71% of participants reported ease discussing the end of life (Graph 19).

Finally, two questions were asked about education in secondary and post-secondary institutions as part of the feasibility study that informed the study design for the subsequent thesis proposal (see Appendix A). When asked whether death and dying should be a formal component of high school education, 51% of participants expressed uncertainty and responded "maybe," 32% of respondents affirmed the institution of such curricula, and 17% did not believe high school to be a place for end-of-life conversations (Graph 20).When transitioning to post-secondary institutions and colleges, participants were asked about whether death and dying should be formally introduced in curricula. 48% of respondents affirmed the institution of such conversation, 38% were uncertain, and 14% declined inclusion (Graph 21). In comparing the two questions, there is clearly an increase in preference to include education about end-of-life conversations, palliative care, and death and dying in post-secondary institutions (Graph 22).

Providing Space: Potential for Future Sustained Undergraduate Engagement. Given the results from the feasibility study, it is clear that many or most emerging adults lack health literacy to engage in end-of-life decision-making. The question becomes, when and where does education about the topic occur? While ideally it occurs with a trained medical professional in a medical visit, there are significant time and training constraints on physician visits. Physicians are not trained to facilitate such dialogue and utilize vague language that is often too complex for patients to comprehend. Tulsky explains that teachers are not pressured from the same “15- to 20-minute office visits” that primary physicians are restricted to (447). More sustained conversations must be facilitated outside of the physician visit to fully understand “less clear-cut predicaments surrounding end-of-life care” (446). Given the preliminary results of the feasibility study, engaging healthy emerging adults in an undergraduate classroom may help facilitate conversations about palliative care end death.

CHAPTER FIVE:

DEVELOPMENT OF AN EMORY UNDERGRADUATE PALLIATIVE CARE CURRICULUM

Collaboration with the Arthur Vining Davis Foundations. The Arthur Vining Davis Foundations (AVDF) were formed in 1952, under a living trust established by Arthur Vining Davis ("Our Founder and History: Arthur Vining Davis, 1867-1962"). Davis became the president and CEO of the Aluminum Company of America in 1910, and was heavily involved in philanthropy and community work over the course of his tenure as president. After Davis died in 1962 at 95-years-old, his legacy carried on through the Foundations, granting over $300 million to colleges, universities, and hospitals to further scientific inquiry, educational research, and interventions for underserved and vulnerable populations. Broadly, the Foundations seek to "strengthen America's intellectual life, humane instincts and democracy through philanthropic support for private higher education; interfaith leadership and religious literacy; public educational media; environmental engagement, stewardship and solutions; and palliative care."

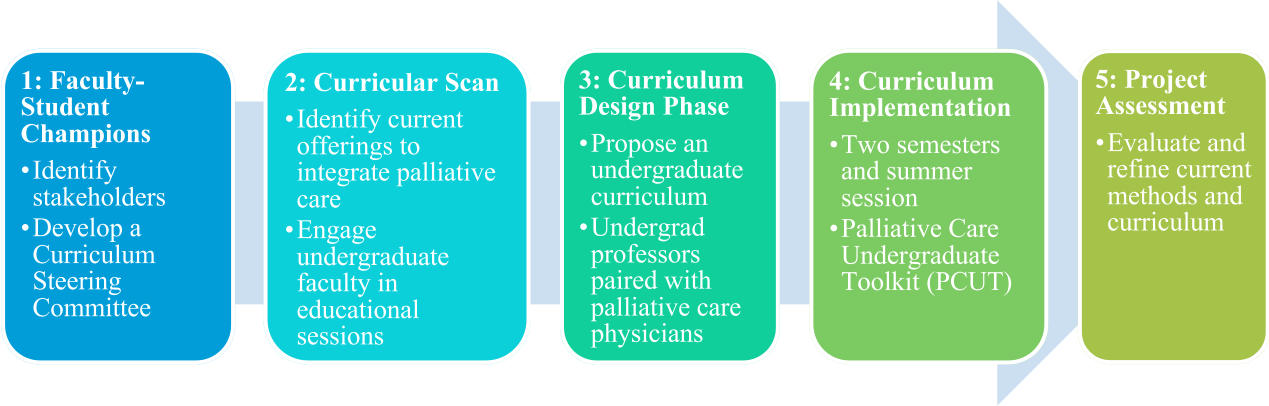
Noting the historically evolving hospice care movement in the U.S., AVDF has funded hospice programs, hospitals, and academic institutions that "have enhanced medical education, the patient experience, and the quality of healthcare in America" ("Palliative Care"). In fact, AVDF funded a grant for the Connecticut Hospice in 1976. This original gift widened the access to end-of-life care and set a precedent for hospice programs that came after throughout America.

As the hospice movement evolved in the late 20th century and into an established palliative care subspecialty, AVDF shifted organizationally and refocused its efforts on supporting and growing research, access, and standards in the field. The Foundation's focus is twofold—influencing the way in which individuals experience a "good death" as well as encouraging the embracement of a "good life," even for those living with terminal illness. This duality is evident in the underpinnings of palliative care with the focus on end-of-life planning, and with an emphasis on meaning-making through vulnerable and honest communication in a physician-patient relationship. As such, to improve upon current practice and research, explore new medical therapies, broaden public awareness of the field, and enhance patient and family outcomes, AVDF funds initiatives that impact palliative care research in pediatric and adult populations; interfaith and spiritual interventions at end-of-life care; access to palliative care services; and curriculum development, amongst other initiatives.

Grant Development at Emory University. In partnership with faculty at the Institute for the Liberal Arts (ILA) at the Emory College of Arts and Sciences (ECAS), the faculty of the Emory School of Medicine (SOM) Division of Palliative Medicine applied for an AVDF grant to fund a palliative care project within the undergraduate curriculum. The proposal, "Integration of Palliative Care with Undergraduate Education," highlights the impact palliative care can have on budding professionals. For those who are able to attend and seek out undergraduate education, college marks a crucial transitional point between childhood and adulthood. With a relatively recent shift to accept palliative care within mainstream medicine, education about the field occurs largely within professional programs and graduate schools, at the master's, doctoral, or residency level. However, to date, there has been little to no focus on exposing undergraduate students who plan to enter a variety of fields to palliative care core principles as part of their curriculum.

Emory University provides fertile ground for engaging in interdisciplinary dialogue about palliative care at both an undergraduate and graduate levels. As a Research One liberal arts institution, Emory's infrastructure includes a highly developed Center for Ethics, a multidisciplinary Center for Contemplative Science & Compassion-Based Ethics, a well-known college of arts and sciences, and a highly regarded school of medicine. All of these departments and programs provide an opportunity to develop an integral program focused on end-of-life and palliative care issues. As such, the proposal was approved, and a $315,000 grant was awarded to the professionals in the SOM and ILA to develop an undergraduate curriculum in March 2019. Under the auspices of the grant, the curriculum development process will ultimately inform a toolkit that can be tested and implemented on other undergraduate campuses.

To holistically construct the interdisciplinary curriculum over three years, the proposal suggested a five-step process: 1) Faculty-Student Champions and Engagement at Emory; 2) Curricular Scan; 3) Curriculum Design Phase; 4) Curriculum Implementation; and 5) Project Assessment (see fig. 2).



1: Faculty-Student Champions
- Identify stakeholders
- Develop a Curriculum Steering Committee

2: Curricular Scan
- Identify current offerings to integrate palliative care
- Engage undergraduate faculty in educational sessions

3: Curriculum Design Phase
- Propose an undergraduate curriculum
- Undergrad professors paired with palliative care physicians

4: Curriculum Implementation
- Two semesters and summer session
- Palliative Care Undergraduate Toolkit (PCUT)

5: Project Assessment
- Evaluate and refine current methods and curriculum

Figure 2: Integration of Palliative Care with Undergraduate Education at Emory University (2019-2022)

The first stage, Faculty-Student Champions and Engagement at Emory, aimed to identify potential individuals across departments in order to best utilize the skills of medical professionals, undergraduate educators, and interested students. Together, the Curriculum Steering Committee (CSC) was developed to act as an advisory body during course implementation and outcomes analysis. Additional cross-university faculty in SOM and ECAS were consulted for public seminars, discussion groups, workshops, and book clubs offered throughout the semester. The second stage, Curricular Scan, examined all current undergraduate courses aligned adjacently with palliative care education content. Courses were identified in many disciplinary areas, including business, anthropology, linguistics, sociology, material and biological sciences, and liberal arts. The first and second stages are continually evolving processes that may change over the course of the grant, depending on the specific semester course offerings.

The final three stages are also malleable and variable, depending on the semester and coordination of the CSC. The third stage, Curriculum Design Phase, enables the CSC to assist in brainstorming processes for introducing palliative care content to current course offerings, alongside the specific teaching faculty. Offerings may take shape in a variety of ways, including research projects, theses, observer-ships/practicums, essays, and seminars all related to palliative care. The fourth stage, Curriculum Implementation, will take place over two semesters and a summer session. At the end of this stage, the palliative care content and offerings will be integrated into the curriculum. These materials will also be added to the Palliative Care Undergraduate Toolkit (PCUT) for eventual dissemination to other undergraduate institutions. And finally, the fifth stage, Project Assessment, will analyze the work of the CSC and evaluate best methods to relay to the field and include in the PCUT for future iterations of the undergraduate palliative care curriculum.

Pilot Course Development & IDS 205W Implementation. As part of the third stage, Drs. Arri Eisen and Kim Loudermilk, faculty within the ILA, developed a pilot course as part of the Curriculum Design Phase.[1] The course, IDS 205W *Science and the Nature of Evidence* ("IDS 205W"), is offered each semester with a different iteration of the central theme. In Fall 2019, the

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[1] Note: I was intimately involved in the development of the IDS 205W pilot course and acted as the undergraduate teaching assistant during for the Fall 2019 course. I served subsequently as the primary researcher for this honors thesis project and course evaluation, with permission of Dr. Arri Eisen.

course was piloted, focusing on the theme of and concepts related to "Death, Dying, and Finding Meaning." The interdisciplinary nature of the course allowed for various elements of palliative care education to be integrated into the readings, assignments, and discussions that occur throughout the semester. IDS 205W takes a holistic approach to questioning through engaging students from various majors, academic and personal backgrounds. At the core of this pedagogical model of teaching, taught by Eisen, the course explored "science as a social enterprise" and through that discourse of questioning examines "a complex human issue or question… from [students] personal experiences and diverse disciplinary backgrounds" (per syllabus). With support from the AVDF grant, this course was designed to eventually serve as a model for other undergraduate course offerings across the nation.

The interdisciplinary nature of the course was evident just from the teaching faculty themselves. Eisen is a Professor of Pedagogy in the Department of Biology with specific training in biochemistry. An 'interdisciplinarian' by nature, Eisen also serves as faculty in the ILA and Center for Ethics, with a specific interest in research ethics and responsible conduct in research education. Loudermilk is a self-described "humanist" with postgraduate training in interdisciplinary studies. Her expertise is specifically at the nexus of media, contemporary American fiction, social movements, and higher education administration.

Together, Eisen and Loudermilk designed an experimental curriculum to be taught from August to December 2019. The writing seminar was offered through the Emory College of Arts and Sciences. It was marketed to second-, third-, and fourth-year students, and required a short application and permission code to enroll. IDS 205W is particularly attractive to students in the College looking to fulfill the writing credit as a general education requirement, and for Interdisciplinary Studies majors hoping to complete a foundational ILA course (when taken with the co-requisite ENG 223 Rhetorical Grammar). Though IDS 205W is typically marketed as a larger discussion class—for up to 20-25 students—this pilot course was intentionally designed to be small, due to the sensitive nature of the content. Thirteen students enrolled in the course from a variety of disciplinary backgrounds and majors, including business, interdisciplinary studies, American studies, music, linguistics, anthropology, and biology, amongst others.

The course consisted of five core academic components: check-ins/extrapolations; personal statements; faculty- and student-led discussion sessions; a final paper; and a cumulative poster. ‘Check-ins’ are purposefully integrated into the pedagogical model of IDS 205W. At the beginning of each class meeting, students and faculty were offered the opportunity to share ways in which the course content related to their everyday lives. This extrapolation took many forms. Oftentimes, it included students speaking to their personal interpretations of the readings assigned for class; for example, students would connect Gawande’s *Being Mortal* to their experiences with grandparents in assisted living facilities. Students would layer information learned from other courses—past and present—that influenced their understanding of the material presented in IDS 205W. ‘Check-ins’ also provided a unique, safe, and vulnerable space for introspection and emotional support. For example, as the semester began, a second-year student lost his life in a presumed suicide. Some of the students in IDS 205W were close to this particular individual. The opportunity to share their personal experience—how death intimately affects even college students, still presumed to maintain their ‘innocence’—was an eye-opening and centering experience for all students taking and faculty involved in the course. Furthermore, after a student’s sister tragically died during the semester, his personal experience inevitably impacted the trajectory of the course content once again. ‘Check-ins’ offered the opportunity to draft messages of support for the student and his family. Though it was not surprising that these tragic events occur naturally in the lifecycle of an adult, discussing them in class with undergraduates in relation to course material was a crucial component of the course. Ultimately, ‘check-ins’ offered the faculty an opportunity to gear content around certain stressors and better gauge the ‘state’ of the classroom.

‘Check-ins’ were supplemented and followed by personal statements. Personal statements offer students the opportunity to draw on personal experiences and relate them to course content, in a deeper and more intentional way than ‘check-ins.’ Modeled after the personal statements of the teaching team, students are encouraged to introduce themselves to their classmates and to share reflections on their own lives in relation to death and dying. This quickly engages individual experience, enhances deep relationship building amongst the students, and sets the foundation for the tone of the course. Personal statements were paired with faculty- and student-led discussions that occurred throughout the semester. The semester was split into four sections: I) Is science right?; II) How we die, memoir; III) Dying different: across cultures; and IV) The biology of death. The syllabus proposed several existential questions for which the course, personal statements, and discussions explored: “Why do you believe what you believe? What are the roots of those beliefs? What kinds of evidence do you accept, consciously or not?”. Ultimately, the core of the discussions sought to investigate methods of inquiry and questioning. Through the underlying focus of palliative care, death, and finding meaning, students were encouraged to introspect on their own preconceived perceptions about end-of-life care.

Interdisciplinary literature provided a fertile resource for exploring the aforementioned existential questions and preconceived perspectives. As part of the course content, three books were chosen to supplement reflective assignments and spur class discussion: *The Cure Within: A History of Mind-Body Medicine* by Anne Harrington; *When Breath Becomes Air* by Paul

Kalanithi; and *Being Mortal: Medicine and What Matters in the End* by Atul Gawande. All three texts related to science, evidence, death, palliative care, and ethics, and collectively drove class dialogue. Students were encouraged to draw upon content in assigned readings as part of their student-led discussion sessions. Faculty- and student-led sessions ranged in themes from spirituality and religion in end-of-life care; cultural differences in funeral and burial practices; complexities of pediatric palliative care; human reactions to pet death; ethics of physician-assisted death; death behind bars: unethical notification and communication of prisoner deaths; evolution of care of older adults in the U.S.; and ethics of life-support and invasive life-saving procedures, amongst other topics. Students were grouped in teams and encouraged to draw upon original experience and content in assigned readings to inform their discussion sessions.

Student teams leading discussions sessions submitted material specifically dedicated to their topic days prior, which was subsequently distributed to the class. Students were prompted with questions to brainstorm. One pair of students, for example, focused their session on the role that spirituality plays in medicine and how it influences practices after death. In this case, the discussion leaders encouraged students to think about their own funeral and those of their friends and family: "Have you attended a funeral? Do you believe this process was intended to support the deceased or comfort and soothe the bereaved in their acceptance of death? How would you ask your loved ones to plan your funeral? Where would it take place, who would attend, who would speak?" The readings, in this case, enhanced the conversation, bringing in evidence and current studies that show the impact of religion on nurses and physicians involved in end-of-life care. Many of these student-initiated topics evolved into project proposals and, in turn, final papers and posters.

Guest lectures by leading experts in the fields of palliative care and end-of-life care—across cultures and specialties—were interspersed into class sessions. Drs. Tammie Quest, Lynn O'Neill, and Jesse Soodalter, faculty at the SOM Division of Palliative Medicine, attended various sessions of the course to teach both formally and informally about the foundations of palliative care and hospice medicine. Geshe Dadul Namgyal, a faculty member and monastic scholar for the Emory-Tibet Science Initiative, taught about Tibetan Buddhist practices at the end of life and reincarnation. His lecture focused on cultural differences at the end of life, specifically *Tukdam*, a meditative practice during the period of death of a Buddhist master that ultimately results in reincarnation according to traditional Buddhist philosophy. Dr. Joel Zivot, a faculty member in the SOM Division of Anesthesiology and Critical Care, provided an opposing perspective to palliative medicine. Zivot highlighted philosophical and practical differences in intensive care, as compared to palliative care, and proposed personal ideologies about a physician's duty to a dying patient. To conclude the guest lecture series, students participated in a session at the Michael C. Carlos Museum at Emory with Elizabeth Hornor, the Senior Director of Education. The students enrolled in the course and faculty engaged with the CSC explored the permanent collection of artwork from ancient Egypt, Nubia, and the Near East; Greece and Rome; the Americans; and Africa, much of it relating to funeral and burial practices, and other cultural celebrations at the end of life. The tour culminated in a dinner during which students and faculty reflected on what they had learned in the museum and integrated that knowledge with previous discussions in the class.

Over the course of the semester, students worked in groups and individually to brainstorm a two-part final project, consisting of a final paper and a poster presentation. The paper development started early on in the course, and was informed by personal statements, guest lectures, extra-curricular experiences, and course discussion sessions. Students were instructed to develop a 5,000-word paper with a strong research question, synthesis of literature, and an original piece, which could include an interview or video, for example. Deadlines were placed at strategic intervals throughout the semester to encourage paper development in stages. To conclude the course, students displayed their written pieces in poster form on the last day of class. Faculty and students perused the classroom to understand the work of their peers, and gain a more holistic perspective on the course content.

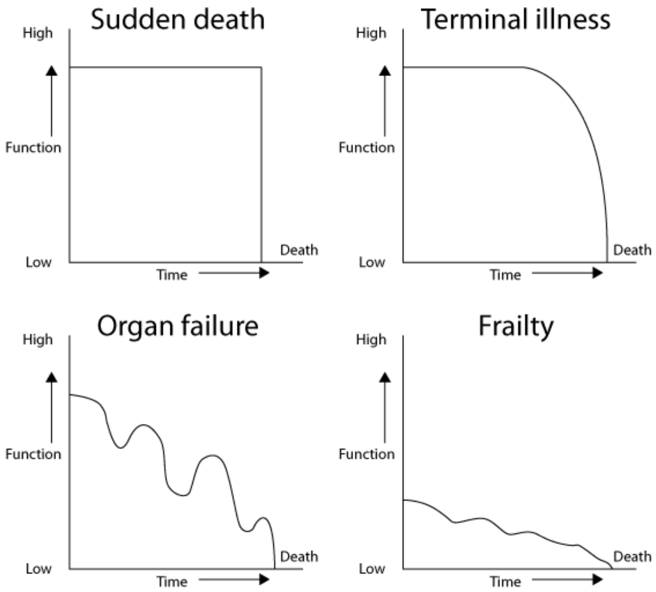

Sudden death
Terminal illness
Organ failure
Frailty

Figure 3: Trajectories of Dying ("Typical Death Trajectory")

Final projects were diverse and individual, and included: the psychological impact of trauma and torture; social perception of death as driven by divisive language used to describe abortions; life and death traditions in the Gullah community (an African American community in the Lowcountry region and Sea Islands of the U.S.); and identification of Kübler-Ross grief stages in near-death experiences, amongst other topics. To highlight one specific project as an example, one student focused on the relationship of music theory and end-of-life trajectories. Grounding his final paper in an interdisciplinary medical and historical context, he attempts to ask how “historians’ and palliative care doctors’ common methods may be applied to the analysis of musical composition.” In his paper, he integrates the commonly used palliative care death trajectories into an analysis of the chorus and verse of The Beatles, “I Want You (She’s So Heavy).” In summary, he paired the four trajectories in an analysis based on the musical and tonal elements. Variations in loudness, harmonies, lyrics, and tempo were mapped alongside sudden death, terminal illness, organ failure, and frailty curves (see fig. 3) (“Typical Death Trajectory”). Interdisciplinary projects, grounded in personal life experiences and passions, rounded out the content and provided students with a final product to share with others—family members, friends, peers, and professors—in and outside of the course.

CHAPTER SIX:

EVALUATION OF IDS 205W: A MIXED-METHODS STUDY

While there is currently a wealth of literature justifying the importance of end-of-life conversations with emerging adults suffering from chronic and terminal illnesses, the research—both quantitative and qualitative—in communication with healthy emerging adults is lacking. Palliative care principles and foundations—focusing on decision-making, health communication, ACP, and holistic care—apply beyond intimate conversations at the hospital bedside, and could have potential practical implications for the lives of emerging adults. To investigate this theory, a study was developed to gauge the efficacy of the pilot course. After the feasibility study showed promising potential for palliative care education and dialogue in an undergraduate environment, this study aimed to gauge quantitative and qualitative feedback from the students enrolled in IDS 205W.

Aims. The descriptive anecdotal study and thesis seek to provide a systematic description of the development and implementation of a new palliative care undergraduate curriculum, guiding further development of the course and recommendations for the PCUT. Ultimately, the study seeks to evaluate the efficacy of a pilot undergraduate course in palliative care in order to effectively draw conclusions about standardization of a future curriculum geared towards healthy undergraduates about death and dying at Emory and other institutions.

Institutional Review Board Process & Approval. An IRB protocol (IRB00116952) was designed alongside Drs. Arri Eisen (principal investigator) and Robyn Fivush, and submitted for review in November 2019. The consent documentation and protocol were approved and determined as exempt from further IRB review and approval on December 3, 2019. As the primary researcher, I completed CITI certifications in Sociobehavioral IRB Training (Feb. 2019) and Good Clinical Practice Training (May 2019) prior to collecting data.

Methodology & Study Design. All enrolled undergraduate students—18 years of age or older—and previously enrolled in the IDS 205W pilot course were eligible to participate. At the end of the course in Fall 2019, students were emailed an online Google Form—with integrated IRB consent documentation—and asked to participate at their convenience alongside course evaluations. Students were recruited both during class and sent a targeted recruitment email. Completion of the online form was completely voluntary and anonymous, and respondents were instructed that completing the evaluation would have no impact on their final grade. There was no compensation for participating in the study. No identifiers were collected during the online survey questionnaire.

The questionnaire was designed with three core sections: 1) Demographics; 2) Course Feedback; and 3) End-of-Life Communication (see Appendix C). The first section inquired about academic major, year in school, age, and course enrollment. The second section contained both quantitative and qualitative questions to gauge the efficacy of the course and comfort with material taught. The third section aimed to quantitatively understand terminology used when discussing palliative care and end-of-life issues, as well as personal practices.

Demographics. Of the 13 students enrolled in the course, seven (n=7) completed the approximately 20-minute survey. Respondents ranged in age from 19- to 22-years-old, all enrolled as undergraduate students at Emory and in IDS 205W during the Fall 2019 semester (Graph 23). Of the respondents, 14.3% (1/7) were second-year students, 28.6% (2/7) were third-year students, and 57.1% (4/7) were fourth-year students (Graph 24). Majors included American

Studies, International Studies, Interdisciplinary Studies, Business Administration, Chemistry, English & Creative Writing, Music, and Linguistics.

Quantitative Results: Awareness of Palliative Care Terminology & Tools (see Appendix D). The third section pertained to personal understanding of palliative care-related tools and terminology, as well as gauged students' participation in previous conversations about the end of life. None of the respondents reported diagnosis of a chronic or life-limiting condition/illness. As described above, a diagnosis of chronic or terminal illness often results in increased chances of planning for and discussing the end of life. When asked if respondents had previous conversation with parents or legal guardians about their personal wishes for the end of life, none of the respondents reported previous conversations.

Respondents were asked about three specific tools involved in ACP: ADs, DPOAHs, and DNR orders. Of the seven respondents, 85.7% (6/7) reported knowledge of an AD (Graph 27). When asked retroactively about prior knowledge before taking IDS 205W, only 42.9% (3/7) reported knowledge of an AD, signifying a 42.9% increase in awareness of students with no prior knowledge and potential further explanation of ADs amongst those with prior understanding (Graph 28). Similarly, when asked about awareness of DPOAHs, 57.1% (4/7) of students reported current knowledge of health care proxies and their role in decision-making (Graph 32). Only 28.6% of students reported prior knowledge of DPOAHs, proposing a 28.6% increase in understanding DPOAHs amongst students enrolled in the course who took the survey (Graph 33). Only one student (14.3%) reported speaking generally with their parents/legal guardians about both ADs and DPOAHs (Graphs 30 & 33). The same student also reported completing an AD in the past and had officially designated a DPOAH (Graphs 31 & 36). None of the students surveyed reported speaking with a primary care provider about ADs or DPOAHs

(Graphs 29 & 34). When asked about DNR orders, all respondents (7/7) reported knowledge of the tool (Graph 37), as compared to 71.4% (5/7) before the course (Graph 38). Though awareness of DPOAHs differed slightly from ADs, the results show an increase in understanding of ADs, DPOAHs, and DNR orders amongst students enrolled in IDS 205W.

Qualitative Results & Analysis: Course Content. An open-ended questionnaire was utilized to gauge reasoning for enrolling in the course and efficacy of the course content amongst students who completed the survey. Students reported enrolling in the course because of prior "amazing reviews" from prior iterations of IDS 205W. Another student reflected on their relationship with Eisen specifically, understanding that the course "with him [would] be thought provoking and worth taking." Similarly, a student "heard the course was really thought provoking and heard that the professor was amazing." Three students reflected on taking the course as a means to fulfill a general education science credit or an IDS foundational course. IDS 205W is listed as a science course in the catalogue, but it was more humanities and social science oriented as compared to other lab sciences. While the course was listed publicly as "*Science and the Nature of Evidence*," the focus of the course on death, meaning, and palliative care was not fully elaborated upon in the description. One student explained that though they "did not know the topic of the course was death, dying and making meaning initially… I found out the topic of the class and was excited to take the course." In reflecting on enrollment in the course, they reflected that they "would have been interested in taking the course just out of intellectual curiosity," and would have not been turned away by the anticipated weight of the topic.

Students were provided with a syllabus on the first day of class and discussed the focus of the semester. Respondents were asked about their initial reactions to receiving the syllabus.

Of the seven respondents, four commented on the "sensitive and taboo" nature of the topic, and how it is "rarely discussed" in college and "not something you will often see in a course curriculum." One student reflected on their "fascination with death… [and] with understanding how various groups make meaning of life and death." They explained that:

> *I knew [that spending] 2.5 hours every week devoted to talking about death… was a rare opportunity, and considering the seminar style of the class and the intellectual curiosity of students who tend to take these types of course, I expected that the discussions would be really riveting. I also liked the idea that the students selected for the course were intentionally studying a variety of topics because death is a topic everyone has to deal with and so to not be intimated by the assumption that someone might know more than you—but rather, that someone might just understand something differently from you—really contributed to my confidence in participating in the course.*

Death as a common denominator was also a reason for participating in the course. As the respondents reflected, death is a "universal" and shared experience, and so actively contemplating and discussing death "can be liberating." Though the majority of respondents were "intrigued" by the course content and syllabus, two students reflected on being in "a bit of shock" and feeling "a little unprepared" at first glance.

Respondents were asked about their familiarity with palliative care as a subspecialty of medicine—gauging their understanding before and after the course. Only 28.6% (2/7) students reported prior familiarity with the concept and terminology of "palliative care" before taking the course (Graph 25). Those who reported familiarity with the field explained that they originally held underdeveloped presumptions about palliative care. One respondent noted that they "had been familiar with the word, but could not have defined what field of medicine it was… nor what it looks like." Many students expressed their cursory understanding of palliative care in that the field simply refers to hospice care: "My original interpretation of palliative care was simply doctors that took care of the sick during hospice care." The same respondent introspected on their original conception of palliative care as “not a proper understanding.” Similarly, another respondent commented on their rudimentary understanding of palliative care as a specialty of care solely for “people when they were terminally ill or going to die” in an attempt to “make the process easier.”

When prompted to reflect on their definition and understanding of palliative care medicine and its core tenets after the conclusion of the course, a common theme emerged. Respondents reported a grasp of palliative care medicine as a “holistic” biopsychosocial-spiritual model of care for patients—of all ages—suffering from life-limiting chronic and terminal illnesses, and that palliative care physicians are focused on “much more than diagnosis and treatment.” Most students understood that palliative care enhances the agency of the patient in decision-making, placing an emphasis on “quality over quantity of life” to “re-empower the patient.” One student explained that “palliative care creates a new relationship between patient and doctor in which the patient… makes decisions in conjunction with their doctor to make their end of life [experience] as seamless and enjoyable as possible.” The separation of palliative care and hospice care was also better recognized at the end of the course. One student explained that “palliative care encompasses hospice care but is not limited to it”; another explained that “hospice care takes place sort of as a separate and post-palliative care phase in which one’s conditions are not necessarily worsening, but are terminal.” Ultimately, all respondents recognized the importance of holistic care in acknowledging patient “wishes” at the end of life.

Students were prompted to reflect on their personal experiences through the course and their comfort with end-of-life issues, including their personal reflections on death and dying. The majority of respondents—71.4% (5/7)—reported being comfortable talking about death and dying (Graph 26). Upon being asked to reflect on their own awareness of mortality, students commented that the course enabled them to confront finitude more consciously:

> 1: *I would say that I have always been aware (in the back of my mind) that I was mortal, but taking the class and thinking explicitly about my own death definitely brought it to the forefront. I'm not sure if that would've happened otherwise, unless I experienced death more closely.*
>
> 2: *On a near daily basis… this class did not fail to remind me that life is finite. I think this is an important sentiment to be mindful of as we go about our day to day, and I definitely think this class has heightened my awareness of my own mortality and fragility.*
>
> 3: *Yes, I certainly am [more aware of my mortality] and I'm more aware of mortality around me as well. Unfortunately, with each day we step closer to our demise, but I don't think that's such a bad thing. Death gives life meaning. This class has showed me that I wouldn't want to live forever because I would live as meaningful of a life if I did not die.*

Other students reflected that, while the course did not impact their own awareness of mortality, it encouraged them to be "more observant of the way others deal with death outwardly, whether this is through social media, the services they hold, anything they do after [a] death in relation to that person's life." Similarly, another student explained that the course enhanced their own feelings of mortality "through events in my life that coincided with the course." Another student reflected that the class has "made me more aware of aging, specifically in relation to my parents and grandparents," thus exhibiting extrapolation of the course content into their own life experience. They further commented that though "the process of aging is incredibly frustrating… I better understand my role to comfort [my parents and grandparents] through the aging process, and I hope I have people around me that will do the same." As described in the qualitative responses, the course clearly encouraged more dedicated awareness of mortality.

While awareness of mortality seems to be enhanced by the course content and discussion, acceptance of mortality varied amongst respondents. When prompted to reflect on one's own acceptance of their own mortality, one student commented:

> *Despite the fact that I am now more aware of it, I don't necessarily know if I am any more accepting. I don't know if confronting death in an academic setting on a… biweekly basis [changes] the fact that everyone I love and don't and myself will all die at one point or another. I do not think I am at a place where I am necessarily readily willing to 'accept' my mortality… Being immortal is one thing, but the chance to extend your 20's for a couple more year—why not? is what I thought!*

Other respondents voiced similar feelings of fear in accepting mortality, knowing that, if death were to occur imminently, they would not be ready to die at a young age in college. One student reflected on a recent experience of confronting fear of death in a turbulent plane ride:

> *There had been a lot of issues with the plane before taking off and we were heading into some rough weather to begin with. There was a moment of a lot of turbulence and while I usually am quite calm on these flights I just had a moment of doubt about my safety and [wondered] if I was going to die. [When] this happened before, I usually [tried] to think to myself 'you know what, I have lived a great life and it will be okay.' This time I didn't really think that and the first thing I thought was "I'm not ready to die." I think most people would feel this way because we have plans and things we are looking forward to later that day or the next week or year, and we want to do those things… so of course my reaction was I really don't want to die.*

The same student reflected that their fear of accepting mortality and confronting death was due to their family and friends not being ready to allow them to die—how death at an early age may, in fact, "hurt" families and friends who are not prepared to let a loved one die. Those who were more accepting of their own mortality after taking the course reflected that "death is universal and without it, life has very little meaning. Thinking about death doesn't have to be a negative conversation. It can [be] soothing as much as it is terrifying."

While introspection of personal beliefs about mortality were assessed through the survey, so too was the impact of the course on the daily lives of students who enrolled in IDS 205W.

Respondents were asked about the influence of the course outside of the classroom—the impact on their interactions with peers, families, and parents. Though responses were varied, many of the students noted a newly found openness to thinking about and engaging with the topic directly amongst friends and family. One student reflected that the course "made me think about raising some of the topics with my partner." Though that student had not had the conversation with their partner at time of submission, the respondent explained that they "would've [not] thought about otherwise" before taking the course. One student noticed that they had made a conscious effort to spend "more time with my grandparents" after taking the course. Other respondents noted the indirect impact of the course on their daily interactions with friends and family:

> *I feel as though my sensitivity and respect for the elderly in my life has grown immensely, seeing as they have often told me they have been forced to confront the themes we have discussed in our class and I have now, at the least, begun to grapple with how shocking and challenging that can be. Furthermore, this course has cultivated in me a desire to volunteer at hospice and more deeply understand those 'editorial' moments that people can experience at the end of their lives.*

The survey responses also implicated an unknown willingness of other students who want to participate in future iterations of the course. One respondent explained that though they do not actively discuss the material with their parents, "every time [they] bring up the course with a peer, they always comment that the topic sounds so interesting and usually that it would be something they would want to take as well." The same student "recommended the book *When Breath Becomes Air* to some peers" and has "talked about physician assisted death with some peers." As two students reflected, the IDS 205W course enabled them to think more deeply about their lived experience. One respondent explained that the course provided the foundation to think "critically about the afterlife, my [religious] views, finding meaning, [and] the process of death" and that they "found the discussions in this class to be soothing… while the material of the class was certainly heavy, I enjoyed taking time out of my week to discuss a concept or text surrounding death. I never would do that without this class." Ultimately, the other respondent summarized their experience in that the course "allowed me to think more seriously about those around me… [and] encouraged me to live life like I am dying."

While qualitatively understanding the impact the conversations students were impacted by in the course, the survey also sought out practical and pointed questions about the course itself. Three pointed questions were aimed to gauge the most surprising aspects of the content, the most challenging elements of the conversations, and suggestions for improvements and changes in future semesters. When asked about what most surprised the students about the course, three respondents reflected on the depth and diversity of personal experiences that students shared publicly:

> 1: *I was surprised by how much I learned about my peers. I think it is really important to get to know people around you and I am grateful for the opportunity to learn more about individuals that I wouldn't have gotten to know otherwise.*
>
> 2: *I think I was consistently surprised both by how personal we were asked to get in this course and [by] how much I enjoyed the ensuing effects of doing so in the class.*
>
> 3: *I was surprised by how diverse the experiences in our class [were] in relation to death and trauma through [the] personal statements. People go through some tough stuff in their lives and you wouldn't be able to notice it unless you truly got to know them, or took a course like this.*

Though the personal nature of the conversation may be off-putting for some, death is seemingly relevant for many undergraduate students. As one student reflected, "I feel like this past year, I just knew so many people who passed away; it was likely because I have grown older and entered college." The undergraduate experience, as this respondent explained, is a transition into adulthood and is accompanied by deeply personal and sometimes tragic experiences. As one student remarked, the course "made me think about deep existential questions" and was shocked by "how much I got out of [the course]." Death becomes normal as the aging process progresses, and certainly does not preclude college students. Not only did students recognize the relevance of the content on their own lives, however, but also "how often [this course] was connected to other conversations and topics I was discussing in my other courses," signifying a potential crossover impact in other classes.

When prompted to reflect on what was most challenging about the course, many students remarked that—while the deeply personal element of the course was freeing and "appreciated"—it was also overwhelming and sometimes a barrier to participation in course discussions. Some of the students reflecting that the most challenging component of the course was "feeling comfortable enough to share personal aspect of my own life experience and grappling with the themes of end of life and end of life care." Two other respondents reflected similarly:

> 1: *I think, at times, the class became quite personal in a way that I really appreciated, but also in a way that is difficult to make normal in a classroom… generally [it] is hard to have intimate conversations with acquaintances. I appreciated this opportunity to step out of my comfort zone… it became [sic] more normalized to share personal information. Sometimes what was challenging was that there was so much more to discuss than we had time for.*
>
> 2: *The most challenging aspect of this course was the personal level we were meant to be on with our professors and classmates, especially during the personal statements.*

While the personal nature of discussions seemed to be a barrier and challenge for some respondents, others reflected on the student-led discussion. One student thought "it was hard for me sometimes to see the value in what we were talking about because open discussion highlighting people's opinions is not usually something that is valued in academic spaces." Another explained that the "student-led discussion" was most challenging as "there wasn't really a prompt" explained clearly to drive conversation. Lastly, a respondent explained that the variety of speakers was "productive," but the "cognitive dissonance between the palliative care doctors and Dr. Zivot was challenging." The conflicting perspectives, for some, seemed to be challenging to hold in the same space, but provided insight into competing medical perspectives observed in the clinical environment.

Given this course was offered for the first time as a pilot of the curriculum, improvements are to be expected. The survey provided an ideal platform for qualitative feedback about potential changes to the course in future iterations. Many students alluded to necessary changes to the structure of discussions in the course, proposing that the course be "a little more content driven." Discussions and presentations were perceived to "not be very valuable uses of time," preferring "a more structure setting facilitated by my professors," rather than student-led discussions. Another student remarked that they wish the "class could have been a little bit more challenging and asked more of its participants at times," further noting a need to include more disciplines in the course and explaining that student discussions slowed "the momentum… down quite a bit." Another student reflected that though the "discussions each day… [were] incredibly meaningful, I would assign additional reflection assignments… to force students to truly think about their lives and the people that mean a lot to them in it." An emphasis on more structure academic content was clear in the responses. Two respondents also noted the lack of explanation of the course in the Emory Course Atlas and suggested including "a sentence that the class deals with personal experiences" up front to "help select students more willing to discuss such topics." While the course helped provide "well-rounded information about approaches to death" with the aim to better assist emerging adults in processing death and dying, not all students are certainly interested in engaging with such personal reflections and dialogue. Introducing the theme prior to enrollment may be helpful with recruitment of interested students in future semesters.

Given current research on the efficacy of palliative care education and discussion amongst chronically-ill emerging adults—in addition to the documented support that the biopsychosocial-spiritual holistic approach to healthcare has on the course of an illness—students were asked to reflect on whether a course focused on death, dying, meaning, and palliative care is beneficial in an undergraduate setting. All seven respondents noted a perceived value in taking a course on palliative care in college. While some respondents explained that the course may be more useful for students "interested in medicine," others remarked about the applicability outside of "medicine" in forcing undergraduates to "answer deep existential questions about how we should spend our lives." Two respondents explained that, as compared to those in the "spotlight [like] ER doctors and surgeons," they had not yet explored or "heard of" palliative care, thus it may be beneficial to learn about other specialties of medicine. One respondent was "grateful I had the opportunity to take [the course]" to reflect on their own life experience. They further explained that "students [who are] fully invested in taking the course" and aware of its topics may benefit the most from the class. Noting the conflicting dialogue between the specialties of palliative care and intensive care, one student explained that they see purpose in a course on death and dying, but wondered "if this is an issue because it might be pushing an agenda on people… [as] some disagree with palliative care." Given the variety of opportunities within a course atlas, one respondent explained that while a course on palliative care "isn't going to make the top 60" course list, "that doesn't mean I didn't gain something important from learning about it." They reflected that a course on palliative care may be more applicable for some than others. To sum up their experience in the course and the benefits of palliative care education in an undergraduate curriculum, one respondent noted the value of the course in allowing "me to explore topics, questions, and aspects of the human experiences that I otherwise would not have been able to. I think it was an enormously impactful experience and would highly recommend the course to anyone interested in stepping outside [of] their comfort zone and exploring something not commonly discussed." As exhibited in the feedback from the course, a willingness to discuss historically taboo and stigmatized topics—like death, dying, and palliative care—is necessary, effective, and productive in the context of a college course.

Additional Information: ECAS Course Evaluation. Eight students (8/13) completed the official ECAS Course Evaluation through the online portal, a 61.5% response rate. Of the respondents, 37.5% (3/8) reported taking the course to fulfill a general education requirement, 50% (4/8) for a major/minor course, 12.5% (1/8) as a pre-requisite for another course, and 62.5% (5/8) out of general interest in the subject. When prompted to optionally comment on the course, one student noted that the "course felt too focused on different student's opinions, which [was] interesting, but I felt like I did not learn a lot of factual information." Other students remarked that the course was "one of my favorite classes I've taken at Emory" and an "unbelievably mind-bending experience… absolutely loved it."

Limitations. It is important to note the limitations of this study in accurately depicting IDS 205W and potential implications for the future. The most significant limitation of this study is the sample size of the respondents. Even with repeated emails and a clear recruitment plan, only seven (n=7) students chose to participate in the post-course survey of the 13 enrolled in the course. This made it difficult to thematically categorize and analyze the responses, and limited the opportunity to find significant results from the quantitative portion of the study. The potential for nonresponse and sampling biases are particularly notable, given the limited sample size. In future iterations of the course, enrolling additional students and sampling a larger portion at the conclusion of the course would better assess efficacy of an undergraduate course in palliative care and result in significant conclusions. Additionally, questions about race, gender, and sexual orientation could be included in future surveys to improve demographic understanding of the course enrollment.

Another major limitation of this study—and the overall assertion that an undergraduate course is crucial for development of emerging adults—is that not all emerging adults are enrolled in college. Emory is comprised of a predominantly Caucasian and educated population of individuals who can afford to attend a 4-year private institution. The success of this course may differ at other institutions of varying calibers, public versus private, 4-year versus 2-year programs. Additionally, palliative care education may be necessary in communities beyond undergraduate institutions. Palliative care education may be most relevant and important in communities and amongst individuals that cannot access formal education due to issues of structural inequality and inequity. For students enrolled in 4-year colleges, like Emory, palliative care education seems supportive of the developmental stages of emerging adulthood. However, future efforts should be made to make proactive palliative care discussions accessible to those in the wider community and those who are not currently enrolled in academic institutions through community programming and engagement.

CHAPTER SEVEN:

DISCUSSION & CONCLUSION

IDS 205W *Science and the Nature of Evidence* offered through the ILA in Fall 2019 served as an important pilot and catalyst for an undergraduate palliative care curriculum. Understanding and awareness of crucial end-of-life care tools and terminology increased over the course of the semester, particularly as it relates to ADs, DPOAHs, and DNR orders. Students were able to clearly articulate the holistic approach of palliative care medicine from a more nuanced perspective than reported prior to the course. When asked about comfort level discussing historically stigmatized and taboo topics, the majority of students surveyed (71.4%) reported a level of comfort talking about death with peers in the course. Ultimately, the universality of experience—that every individual is mortal—made the curriculum accessible to all enrolled in the course. Regardless of the individual major or academic concentration, students were able to immerse themselves fully into the course content. Furthermore, this study preliminarily gauged interest in future palliative care courses. Most respondents remarked that a curriculum designed to engage students in end-of-life conversation would be appropriate to include in the course atlas. It is worth noting that while not all students would have enrolled in a course focused on palliative care, course conversation proved effective and helpful, particularly for students with an aligned interest or relevant personal experience. While improvements could be made in future iterations to enhance the content and further challenge students to delve deeper into the material, the pilot course dictates a need and desire of healthy undergraduate students to participate actively in conversations about death and dying.

This honors thesis study begins to unravel the qualitative anecdotal reflections of students engaged in the IDS 205W pilot curriculum. Given the uniqueness of the course curriculum, there is much to be discovered and defined in future offerings of the course. Of note, it is important to better define the core components of the course. Respondents noted a lack of structure and flow to some of the course content and discussions. Defining the value of experiential opportunities—exploring the Carlos Museum, for example—is crucial in determining a pedagogical model for teaching palliative care to undergraduates. Furthermore, understanding the impact of highly personal introspection on the mental health of a healthy emerging adult is suggested for future studies. As noted by some respondents and noted in literature about grief and anxiety about death, there is likely a limit to which discussing death and dying becomes unbearably upsetting and depressing. Engaging in overly personal and borderline uncomfortable conversation about death and dying may have the opposite effect on an undergraduate student: rather than creating a meaningful appreciation of palliative care, discussion may ultimately devalue dialogue about death and dying. Undergraduate students are not morticians or pathologists. Therefore, it is vital to define scaffolding within which faculty can be supportive of undergraduate students who are encouraged to delve deeply into heavy content surrounding end-of-life issues. Crossing the boundaries into unchartered territory by developing a curriculum in palliative care comes with the challenge of exposing emerging adults to an appreciation of difficult conversation, while also preventing unhealthy fatigue and subsequent depression.

Universities, in particular, function as ideal spaces to find the balance in educating emerging adults about end-of-life practices. Emory University serves as an example. In addition to the IDS 205W pilot course, the university has incorporated palliative care into elements of the undergraduate experience outside of the classroom. ‘Death Cafes,’ for example, are offered through the Pre-Health Advising Office at Emory. Death Café was developed as a “social franchise” to engage random assortments of people in conversations about death over tea and cake in temporary and fleeting events. The movement has quickly spread across Europe, North America, and Australia since its movement's founding in 2010. The first Death Café was offered in the United Kingdom in 2011; since, over 10633 Death Cafes have been offered in 70 countries with the goal of talking plainly about death and "to increase awareness of death with a view to helping people make the most of their finite lives" ("What Is Death Cafe?"). In a 2013 feature on NPR, the podcast features a mother and her 7-year-old son participating in a Death Café to help him process the death of his great-grandmother. As the author reflected, the conversation is not solely focused on death itself, but rather "ends up being about not so much how we die by how we live" (Prichep).

Not only have Death Cafes been offered on Emory's campus, but so too additional extra-curricular programming to enhance undergraduate engagement with professionals in palliative care and affiliated fields. In fact, an educational session at the January 2019 Emory Scholars Program Retreat proved to be successful in creating a collaborative and honest environment for conversations about death and dying. A session entitled "The Conversation Project: Engaging Undergraduates in Advance Care Planning for the End of Life" was held for students, many of whom vocally expressed an urgency to discuss end-of-life planning. The students expressed satisfaction after participating in the dialogue amongst their peers. Amongst the other offerings at the retreat, this educational session was rated highest of those offered and received high praise anecdotally from undergraduate students. This session was offered as part of a larger movement within The Conversation Project to publicly engage individuals with one simple goal: "to have every person's wishes for end-of-life care expressed and respected" ("Our Purpose"). The initiative began in 2010 after a movement of medical professionals, writers, clergy, and media shared stories about their perceptions of "'good deaths' and 'hard deaths' within their own circle of loved ones" ("Our Purpose"). The project has partnered with many influential public health researchers and physicians, and has engaged over 740,000 people from 50 states and 160 countries online and through programming to date. The Conversation Starter Kit, used to guide discussion at the Emory Scholars Retreat, has also been translated into many languages.

Emory Student Health Services even provides guidance for developing an AD on their website, highlighting the importance of expecting the unexpected, "[Even though] Emory students are generally very healthy, none of us ever knows if or when we will become incapacitated and unable to make decisions about life sustaining treatment in the face of catastrophic illness or injury" ("Advance Directives"). While there is still much to be done to destigmatize death at Emory, and other college institutions, strides are being made to properly educate students.

Literature on college-specific AD planning, end of life, and death and dying curricula is "in its infancy stage" and studies are sparse (Sanders and Robinson 332). However, this thesis research correlates with current literature that illustrates the important guidance ADs provide after a traumatic and unexpected event occurs in early adulthood. Emerging adults in particular have a newly found responsibility to make decisions for themselves in the medical setting, so college becomes an ideal place for healthcare education. Discussing death and palliative care in constructive educational environments can provide opportunities to "address misconceptions and unrealistic expectations before major medical events occur" (Wiener et al. 902) and correct misperceptions that ACP "is only necessary for older adults or those with life-threatening health conditions" (Sanders and Robinson 329). ADs, for example, have been proven to "reestablish autonomy and sense of purpose" and provides emerging adults with control (Wiener et al. 898). As such, the growing movement continues to proliferate accurate information about the end of life amongst healthy emerging adults who may eventually and similarly “suffer from unexpected medical events” (Sanders and Robinson 329).

Choosing a DPOAH has also proven to assist students in creating and sustaining meaningful relationships with family members and friends—citing a “pivotal point” in discussions about “real-life implications” (340). Educators start “the discussion with young healthy adults about [advance care planning]” (341). By facilitating such conversations amongst healthy individuals in an academic setting, strong family and friend relationships are fostered. A receptiveness towards death helps create peaceful structure, promotes dignity and control, and reinforces the importance of familial support at the end of life long before it occurs.

Post-secondary institutions foster learning environments in which students openly engage in difficult conversations, learn to challenge one another, and determine their own unique perspectives on political and social issues. Emerging adulthood is a time where individuals must begin making informed decision about their future healthcare (Berger 12). Death is inevitably part of the lifecycle; however, ADs, DPOAHs, and death and dying are not often included in the lesson plan. College environments provide fertile ground for death talk, yet common misperceptions continue to prevent such dialogue. The illusion that depression and anxiety will result from engaging in such conversations proves to be a barrier to completion of an AD, and the larger societal misconception and assumption that “healthy, young adults do not need to consider their own mortality” continues to exist (Sanders and Robinson 332). This mentality is detrimental for the 88% of healthy emerging adults who want to engage in end-of-life decision-making (333). As Dr. Dylan T. Lott, an anthropologist at the Center for Healthy Minds at the University of Wisconsin, explains, rather than often fearful, intimidating, and debilitating conversations that perpetuate a taboo of death, it is crucial to create spaces where "people can think fearlessly and clearly" about death (Lott).

The IDS 205W pilot course evidently had a personal impact on many of its participants, facilitated through the innovative teaching of Eisen and Loudermilk, alongside visiting lecturers from a variety of fields and concentrations. After reflecting on his aforementioned final project focused on music theory, one student reflected that "IDS 205W felt to me like a crash-course in talking about hard things. I've never experienced a true feeling of loss, but hearing my classmates share their perspectives on death and dying (and understanding the difference) gave me insight into the process." A second student respondent eloquently summed up his experience in the course:

> *The IDS205W class has been one of the most thought-provoking classes I have ever taken, for, unlike some other classes, it is deeply personally relevant as a human. It has not merely changed what I think or how I think but how I hope to live. Prior to this class, I hadn't looked at death as an essential and necessary part of life, and especially not death in the United States. I had simply hidden from it. While I won't claim that I am close to understanding death, I think I have a greater appreciation for the way it affects our lives, and am perhaps more receptive to further understandings. This class has also made me consider and reconsider the assumptions which I make about the world, and thus has tried to instill a greater degree of epistemic humility, a trait which appears to be helpful in many, if not most environments. I now am not quite so sure of what I know, or at least am more open to questioning how I know what I know. In all, I think this class has made me more open to cognitive dissonance and less afraid of uncertainty.*

As this student explains, learning about death allowed him to recognize the uncertainty of life and internalize a newly found comfort in having confronted death. In fact, this newly appreciated "cognitive dissonance" alludes to the fact that "young people are not passive receivers of these representations but actively, creatively and positively construct their own perspectives on death" (Coombs 300). In fact, as history has proven itself to shift, Western medical thought has slowly come to accept that difficult conversations about death are "beneficial" and are "increasingly considered the standard of care" (Pao and Mahoney 511). As the cycle of life continues, emerging adults will begin to grapple with "constructing meaning in their experiences with death as they come to realize their personal mortality" (Noppe and Noppe 146). An undergraduate classroom, the results suggest, may prove helpful to facilitating this intentional meaning-making around challenging topics.

Playwright George Bernard Shaw explains, "The single biggest problem in communication is the illusion that it has taken place" (Cummings 21). Discourse undergirds the validity and strength of the doctor-patient relationship. As such, conversation between educators and emerging adults is the "fundamental ingredient" of proper end-of-life education and subsequent communication (Roter and Hall; Mishler). Life-limiting conditions, paired with highly complex medical communication, strip emerging adults of the ability to voice their choices and wishes. Ultimately, better communication with emerging adults before the onset of chronic illness enhances autonomy and avoids misalignment of expectations. Educational institutions provide a framework for educating about end-of-life-related tools that circumvents the "profound moral distress" traditionally associated with the end of life (Cummings). This subsequently provides structure for peaceful, healthy, and comfortable conversations between parents, families, healthcare professionals, and healthy emerging adults about death and dying.

What occurs after death is inherently uncertain. However, one thing is certain: all humans are mortal and eventually will die. As exhibited through the survey responses, healthy undergraduates express a clear desire to learn more about their peers. Many of the narratives in response to the IDS 205W course reveal the applicability of death in the daily lives of undergraduates. Emerging adults have intimate and real experiences with death, be it of family members or friends, particularly during the undergraduate years. Emerging adults, their peers, and their families are not immune to suicide, cancer, and other chronic illnesses. It is the role of educators and community physicians to actively discuss death and dying in an effort to destigmatize the topics associated with the end of life. By creating space to have difficult conversations, students are able to learn deeply from the experiences of their peers, develop deep relationships with their professors and mentors, and are able to freely express their full selves in all of the angst, worry, hope, and meaning that accompanies death and dying. The educational space to explore and debate allows emerging adults to become better equipped to make decisions that will inevitably arise at the end of life for both themselves and their loved ones. Ultimately, in welcoming the engagement of conversations about death with undergraduate students through a palliative care curriculum, emerging adults will have the proper educational resources to be the self-authors of their own lives and decisions.

EPILOGUE:

This thesis project has motivated me to search the depths of my hard drive and finally exhume my advance directive. Frankly, I still do not understand it fully. Of the parts I can process—given the highly sophisticated legal language—I do have some questions and changes that I imagine I will want to make now and in the future as I age. I have come to understand that the conversations a person has about the end of life will be many throughout a lifetime and subject to change according to the health and the context in which one lives.

It is clear to me now that even my parents and immediate family members are not immune to the avoidance of discussing death itself. This, in part, I imagine is rooted in the same universal fear of the unknown. Until it was forced upon my parents and me by the shock and trauma of Ezra's sudden death, the conversations that I previously had at the family dinner table were wholly theoretical. I think that the heightened anxiety and fear, brought on by Ezra's death, prompted my mom to write that email I woke up to in December 2015 with my advance directive attached. Although there was little subsequent discussion about her email, it forced me to begin to confront existential questions in a deeply personal way.

Ultimately, this thesis research—paired with my academic interest in palliative care—has enabled me to further address these questions, but I have only scratched the surface. I acknowledge that many of my questions—and those of my peers from IDS 205W—do not have answers. I will approach crossroads in my life where I am forced to make difficult decisions about the end of life, for myself and for others that I love. However, discussing death, dying, and palliative care reduces fear and strengthens belonging, and I intend to continue doing so with my loved ones and friends over the course of my life.

And so, in that spirit, just over four years later—after ongoing thought, mentorship, teaching, and research—I am now ready to reply to my mom's email:

To: Mom <DebbieSnyder123>
From: David <dkulp>
Subject: Re: *send me signed document i sent u the other day—the one about power of attorney*

Dear Mom,

Thanks for sending this (albeit four years ago). Sorry for my delayed response. I've been thinking about the topic and the importance of the document over the last few years. I've taken several classes at Emory, and even had a chance to help design and teach a course focused on death and dying. I've learned a lot, but still recognize that I have many more questions than I do answers.

I figure now is an apt time to talk with you and dad about the details of my advance directive. And maybe we should talk about yours as well… In the meantime, I've signed it, but left some edits in the track changes. Let's be sure to discuss it next time we are all around the dinner table. Looking forward to it!

Luv u,
David

APPENDIX A: Feasibility Study Survey Questions

The following questions were included in the feasibility study for Health Communication in Spring 2019.

Section 1: Demographics
Age? (Between 17-26-years-old)
Are you an undergraduate student? Yes/No
If no, are you a graduate student? Yes/No
Do you attend Emory University? Yes/No
If not, where do you attend school?
What year are you? Freshman, Sophomore, Junior, Senior, Graduate
What is your major/focus of study?

Section 2: End of Life Communication Tools
Advance Directives and Familiarity
Do you know what an advance care directive is? Yes/No
If yes, briefly describe what it is and how it's utilized. (optional)
Has your primary care physician ever spoken to you about an advance directive? Yes/No
Have your parents/legal guardians ever spoken to you about an advance directive? Yes/No
Have you learned about advance directives in an academic course? Yes/No
Have you completed an advance directive in the past? Yes/No

Durable Power of Attorney (Health Care Proxy) and Familiarity
Do you know what a durable power of attorney (health care proxy) is? Yes/No
If yes, briefly describe what it is and how it's utilized. (optional)
Has your primary care physician ever spoken to you about a durable power of attorney? Yes/No
Have your parents/legal guardians ever spoken to you about a durable power of attorney? Yes/No
Have you learned about durable power of attorney in an academic course? Yes/No
Have you designated a durable power of attorney? Yes/No
Do you know what a Do-Not-Resuscitate (DNR) order is? Yes/No

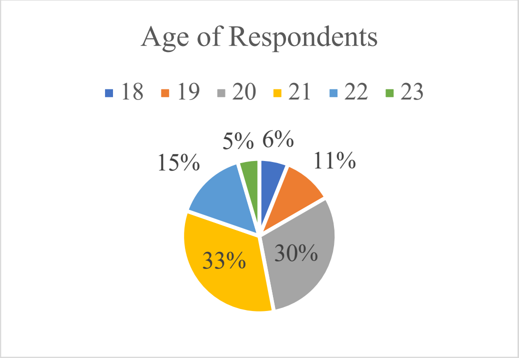
Section 3: Comfort in Discussing End of Life
On a scale from 1 to 10, how difficult is it for you to raise and engage in conversation with your FAMILY about death and dying? (Likert scale, 1-extremely easy/10-extremely difficult)
On a scale from 1 to 10, how difficult is it for you to raise and engage in conversation with your FRIENDS about death and dying? (Likert scale, 1-extremely easy/10-extremely difficult)
Have you spoken to your mother about her wishes for the end of life? Yes/No
Have you spoken to your father about his wishes for the end of life? Yes/No
Have your parents/legal guardians spoken to you about YOUR wishes for the end of life? Yes/No
If you can remember, at what age did you first realize you could die? (Between 5-16-years-old, "I don't remember")
At the current moment, do you feel comfortable talking about death and dying? Yes/No
Do you wish your primary care physician spoke more openly about death and dying? Yes/No

Should death and dying be a component of high school education? Yes/No/Maybe
Briefly explain why it should or should not be a component of high school education. (optional)
Should death and dying be a component of post-secondary education? Yes/No/Maybe
Briefly explain why it should or should not be a component of post-secondary education. (optional)

APPENDIX B: Feasibility Study Survey Results

Section 1: Demographics

GRAPH 1.



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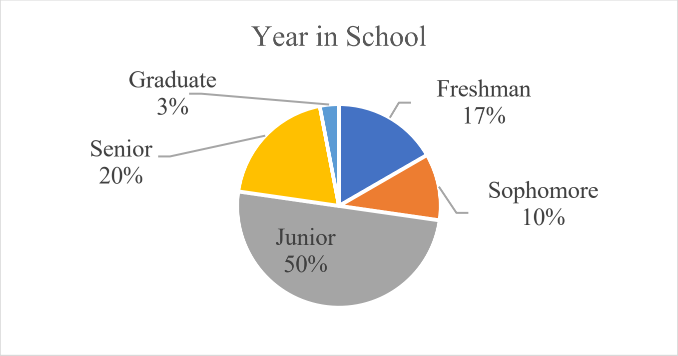
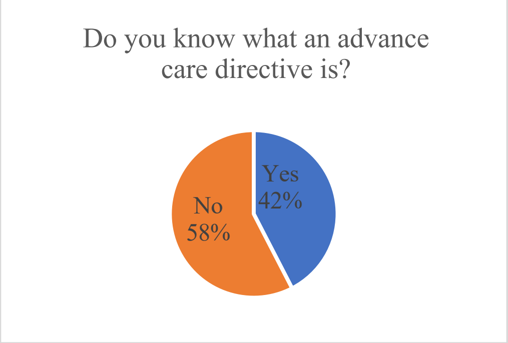


Section 2: End-of-Life Communication Tools and Familiarity

Advance Care Directives

GRAPH 3.



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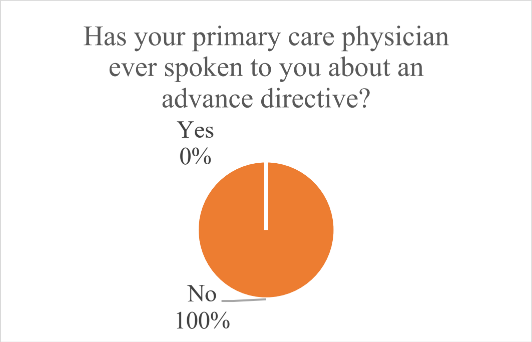

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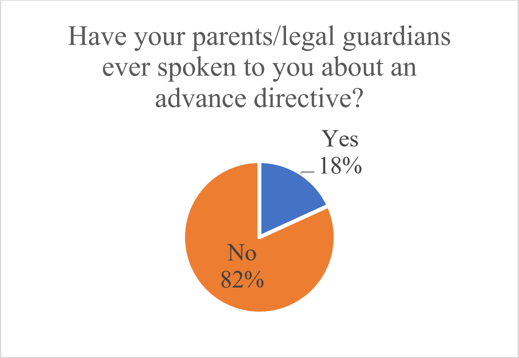

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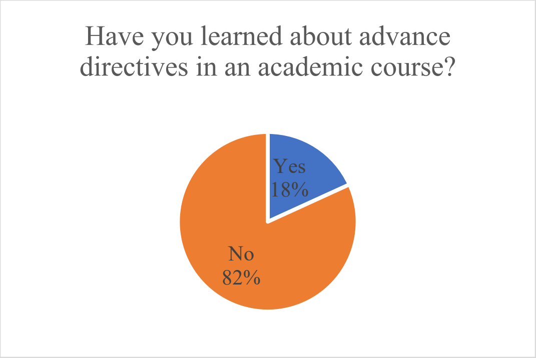

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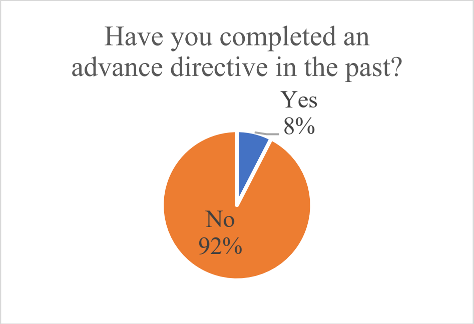
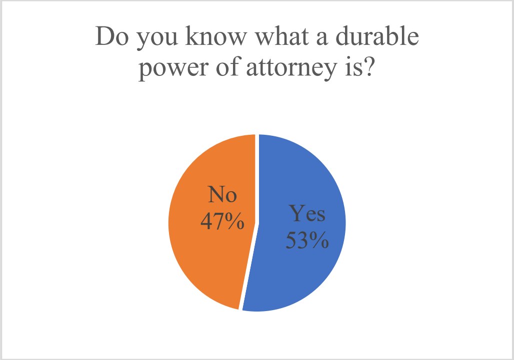
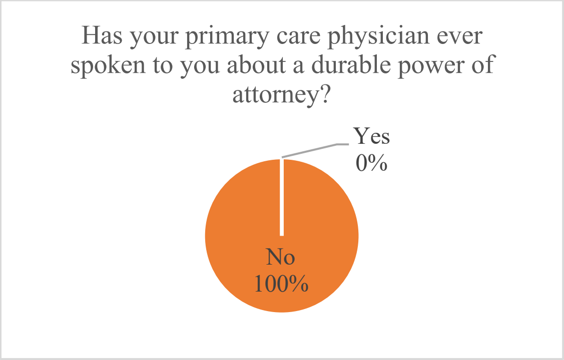


Durable Power of Attorney (Health Care Proxy)

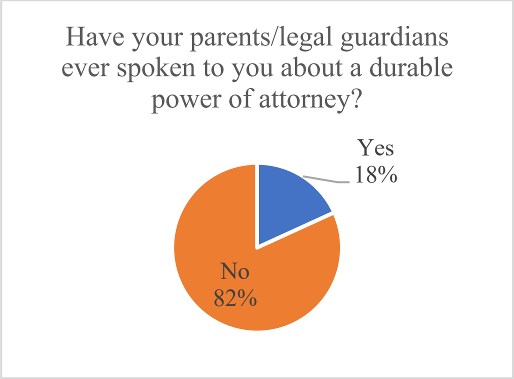
Graph 8.



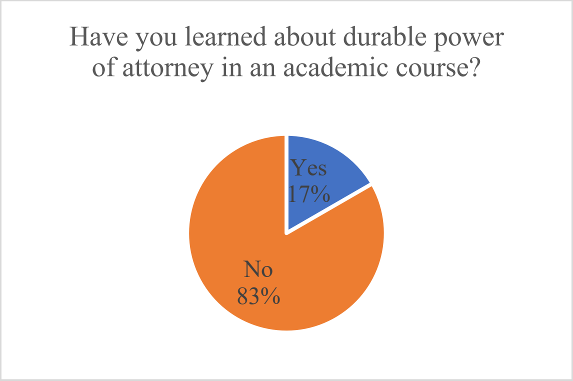
Graph 9.



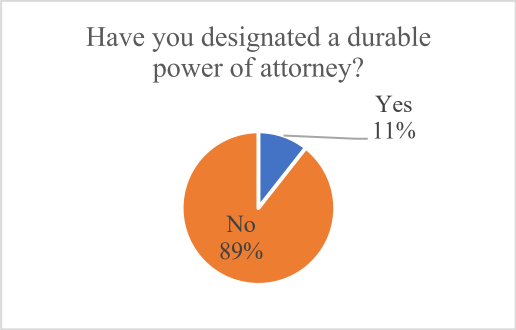
Graph 10.



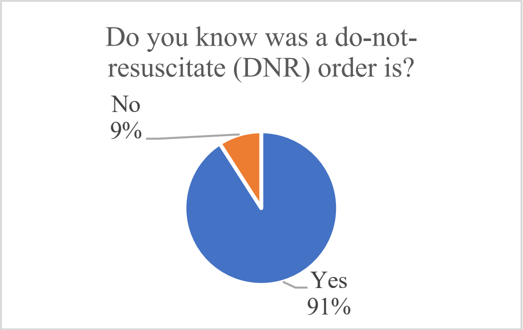
Graph 11.



Graph 12.

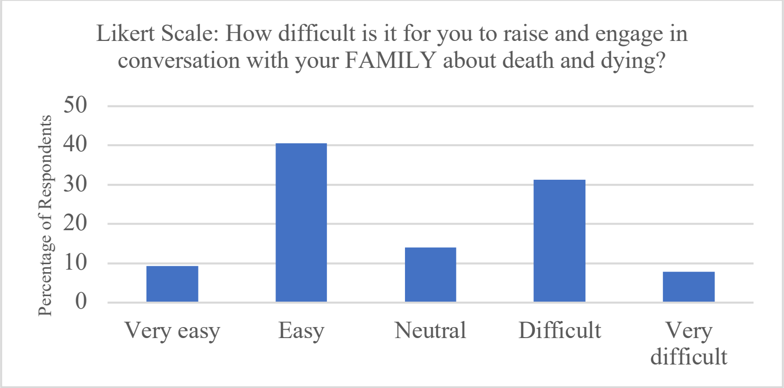


Graph 13. *DNR and Familiarity*

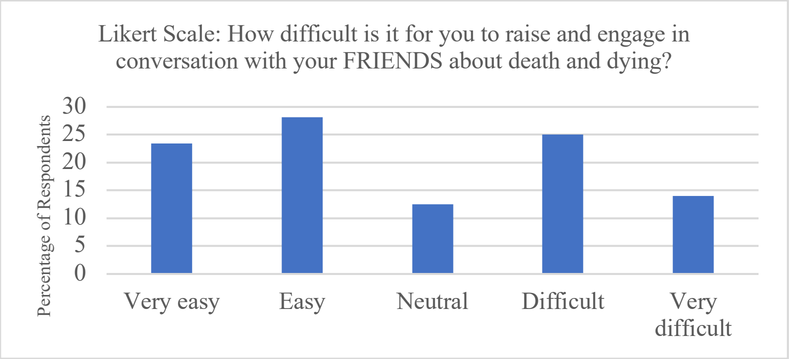


Section 3: Comfort in Discussing End of Life

Graph 14.

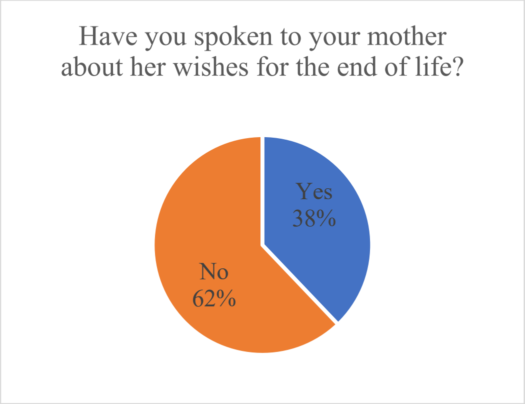


GRAPH 15.

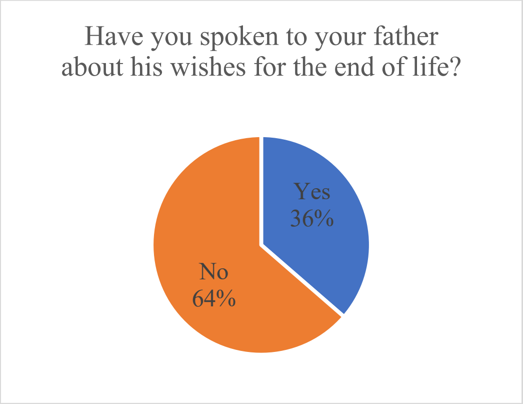


*Likert scale was changed in Excel to a 1 to 5 from a 1 to 10 ratio initially.

GRAPH 16.



GRAPH 17.



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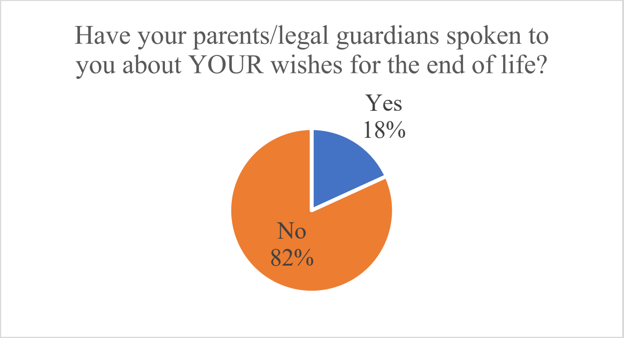

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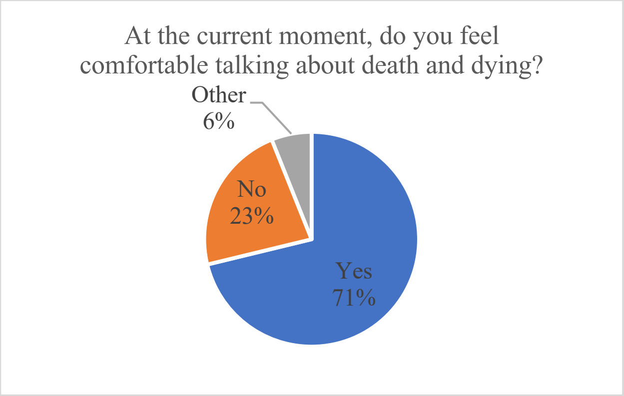

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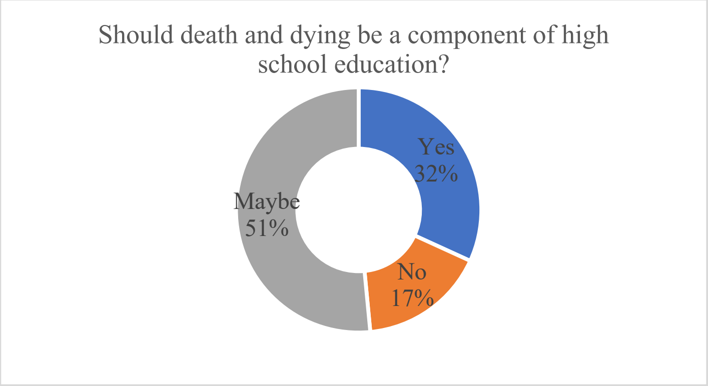

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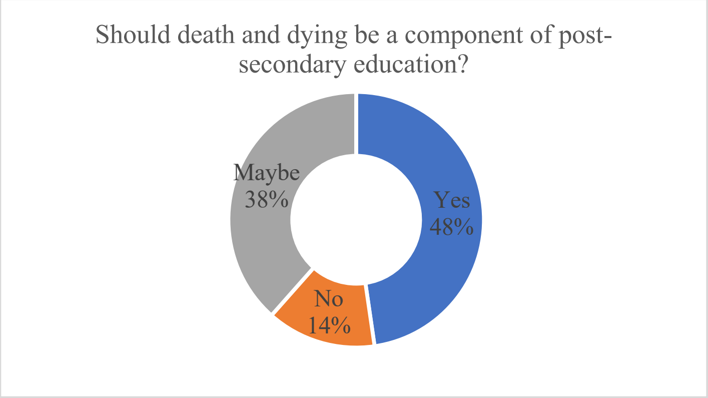
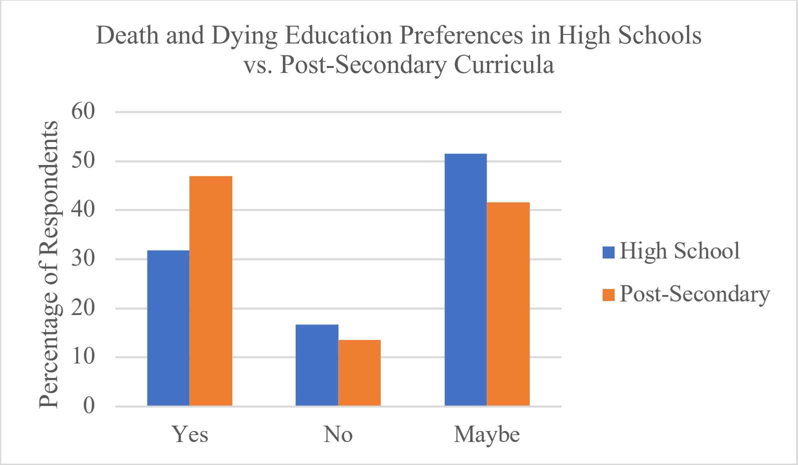


GRAPH 22. *Comparison of Perspectives, Integration of End-of-Life Curricula in High School v. Post-Secondary Institutions*



APPENDIX C: IDS 205W Evaluation Research Instrument

The following survey was used for evaluation of IDS 205W and for this honors thesis study. Informed consent document appeared before questions in the online evaluation (IRB00116952).

Section 1: Demographics

How old are you? (Between 18-23-years-old)
Are you an undergraduate student at Emory? Yes/No
Are you enrolled in IDS205W for the Fall 2019 semester? Yes/No
What year are you? First, Second, Third, Fourth
What is your major?

Section 2: Course Feedback

Why did you decide to take this course?
What intrigued you, if anything, about the topic after receiving the syllabus?
Have you heard of palliative care before the course? Yes/No
If yes, how was it defined/explained previously?
As you've learned it, what is your definition/understanding of palliative care and its tenants now?
Has this course influenced the way in which you interact with your peers? Family? Parents? How so?
At the current moment, do you feel comfortable talking about death and dying? Yes/No
Are you more *aware* of your own mortality after taking this course? How so?
Are you more *accepting* of your own mortality after taking this course? How so?
What surprised you most about this course?
What was most challenging about this course?
What would you change about this course?
What does it mean to live knowing that you're going to die, and having spoken intimately about it in class?
Do you think a course on palliative care is beneficial for undergraduates? Why or why not?

Section 3: End-of-Life Communication

Have you been diagnosed with a chronic or life-limiting condition/illness? Yes/No
Have your parents/legal guardians spoken with you about your wishes for the end-of-life? Yes/No

Advance Care Directives

Do you know what an advance care directive is? Yes/No
Did you know what an advance care directive was before this course? Yes/No
Has your primary care physician ever spoken to you about an advance directive? Yes/No
Have your parents/legal guardians ever spoken to you about an advance directive? Yes/No
Have you completed an advance directive in the past? Yes/No

Health Care Proxy / Durable Power of Attorney

Do you know what a durable power of attorney (health care proxy) is? Yes/No
Did you know what a durable power of attorney (health care proxy) was before this course? Yes/No

Has your primary care physician ever spoken to you about a durable power of attorney? Yes/No
Have your parents/legal guardians ever spoken to you about a durable power of attorney? Yes/No
Have you designated a durable power of attorney? Yes/No

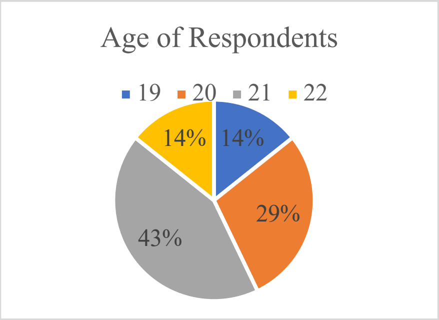
Do-Not-Resuscitate Order
Do you know what a Do-Not-Resuscitate (DNR) order is? Yes/No
Did you know what a DNR order was before this course? Yes/No

Conclusion:
Your response has been collected. Thank you for participating in this survey.

APPENDIX D: IDS 205W Evaluation Study Results

Section 1: Demographics

GRAPH 23.



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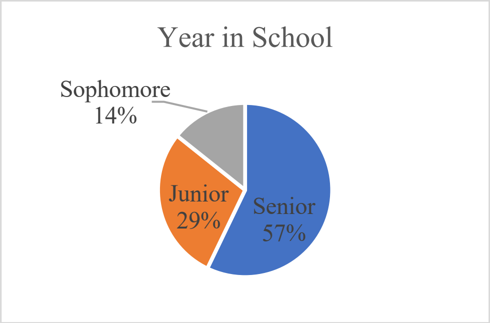
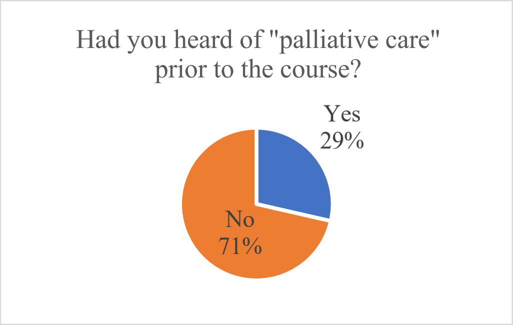


Section 2: Course Feedback

GRAPH 25.



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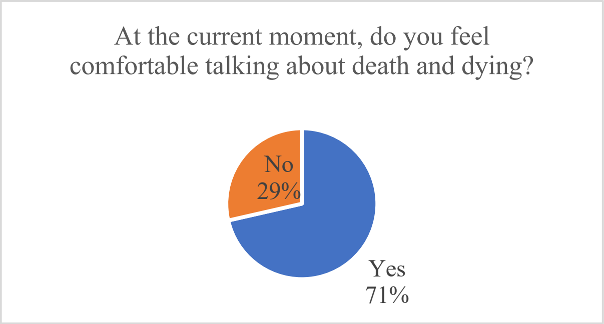
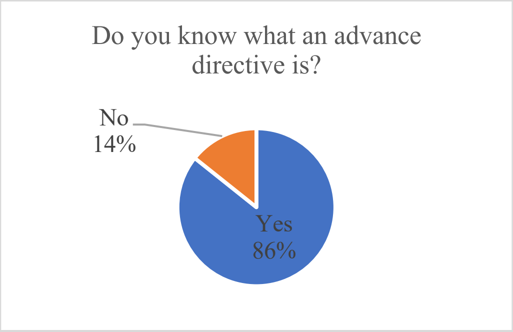


Section 3: End-of-Life Communication

Advance Care Directives

GRAPH 27.



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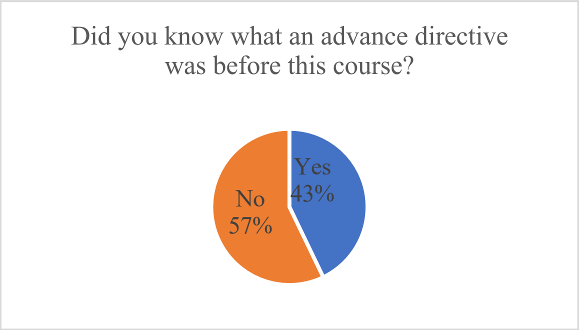

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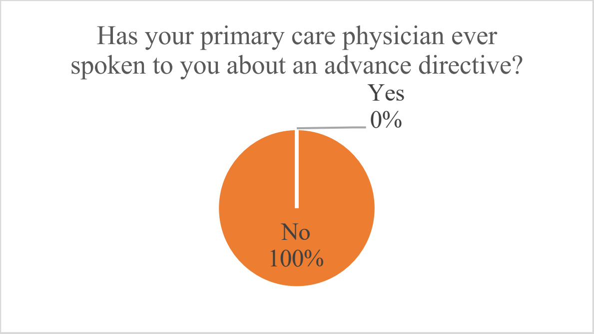

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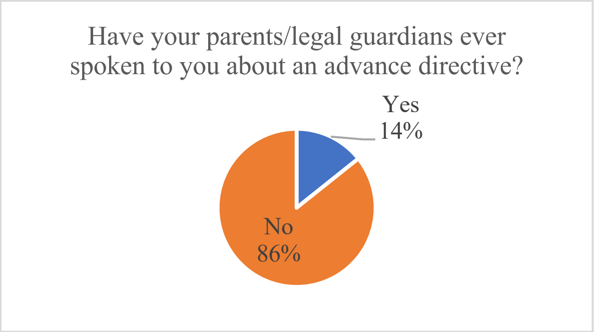
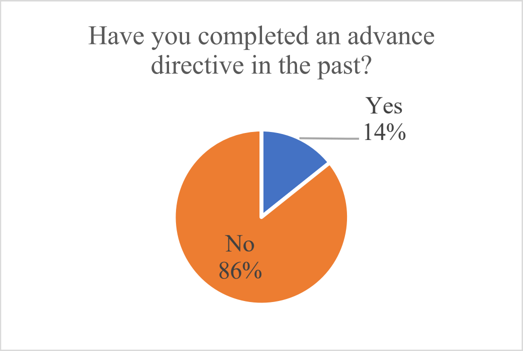
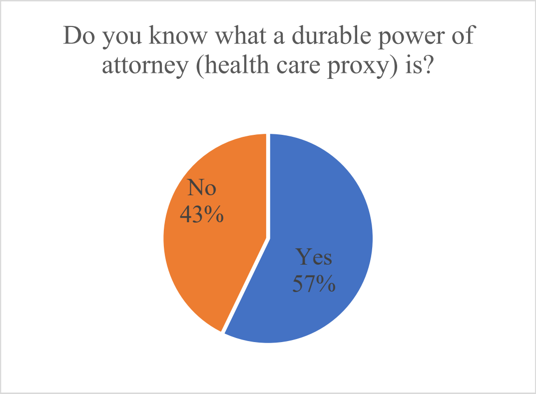


GRAPH 31.

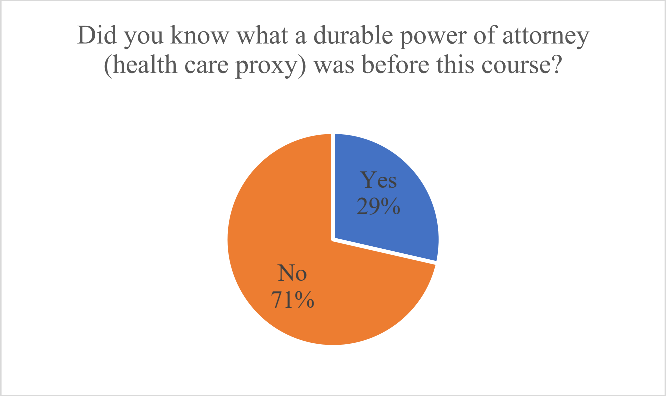


Health Care Proxy / Durable Power of Attorney

GRAPH 32.



GRAPH 33.



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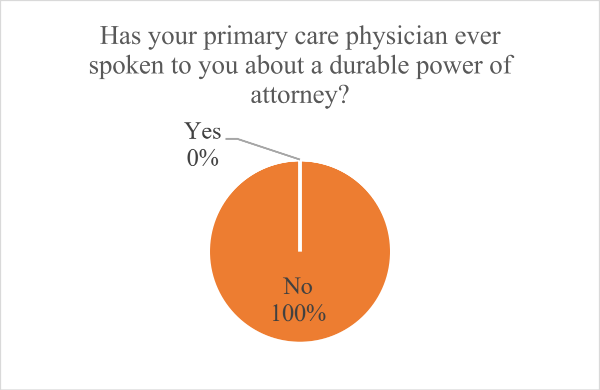

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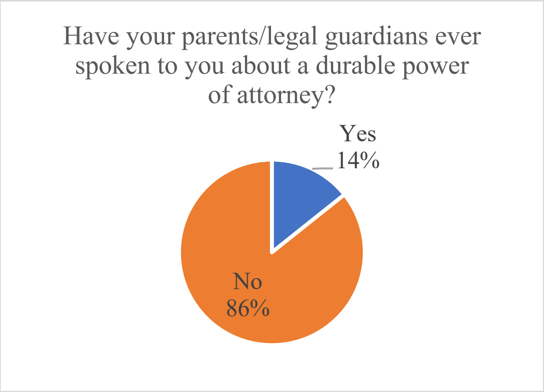

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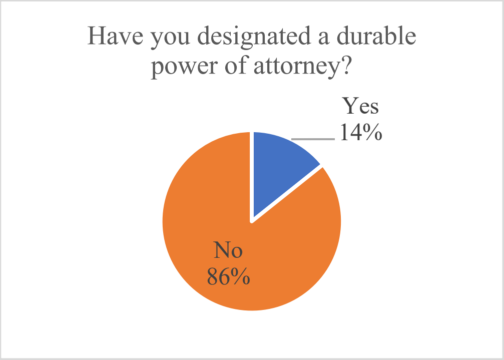
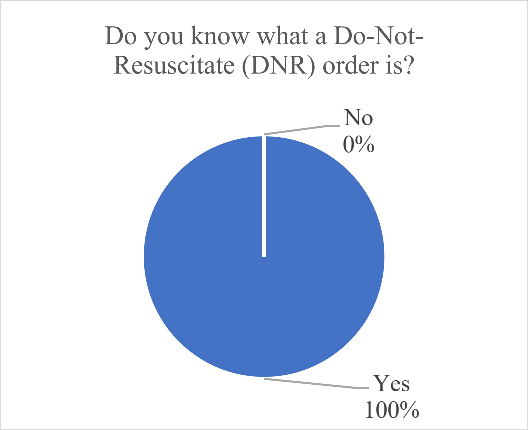
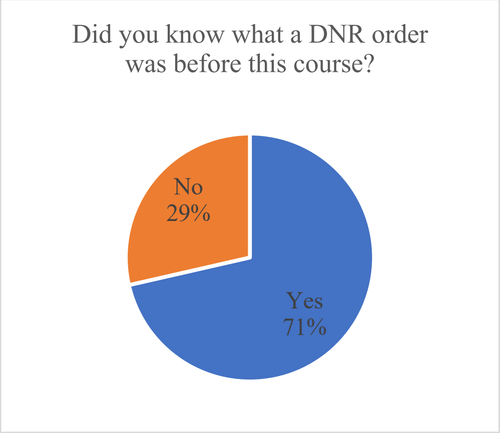


Do-Not-Resuscitate Order

GRAPH 37.



GRAPH 38.



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