

Death and Dying: The Literature, Philosophy, and Practices of Adult and Pediatric End-of-Life Care

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How does one “live a good life?” While it is good to explore what it takes to live a fulfilling life, it is equally important to understand how to confront death. Societally, little to no emphasis is put on death, let alone dying a “good death.” We are immersed in a death-avoidant culture and only give death attention when it impacts us. Is dying a good death possible? What factors play into dying a good death? Does this change when we confront the death of a child— an untimely death? This thesis is comprised of three parts: a general account of dying a good death and the factors it takes to die a good death, pediatric end-of-life care and dying an early death, and the issues that healthcare professionals must consider. This thesis argues that both adults and children are able to die a “good death,” and that certain factors can help with this process. Because the death of a child is nuanced, there are additional factors to consider, such as establishing a legacy and upholding the role of family and loved ones in a child’s death. In the last part, healthcare professionals illustrate how to work with patients in the end-of-life stage, and how healthcare professionals, as human beings, can aid in the dying process. With more attention, the topics of death and dying can be viewed as more than just a taboo.

Introduction

Over time and across the world, the meaning of dying a good death changed depending on the context of the period. During the prehistoric time (between 2,500,000 to 4,000 BCE), humans anticipated death and dying. During a part of this period, the Stone Age, death occurred suddenly and there was no room for reflection of dying or preparing for death (1). Death primarily occurred due to accidents or via predation, which limited the consciousness and prior thinking that went into such an important aspect of life. Therefore, dying a good death was not to be determined by the individual who died. Instead, it was based on what the survivors thought—an odd way to end based on today’s norms and standards.

In the Historical-Pre-Modern Time (from 3500 BCE to the 15th century), the dying experience changed since it was more predictable than before. Most of these deaths were associated with old age or infectious diseases, such as smallpox, which led to dying in a more gradual and prolonged manner in comparison. This allowed the dying to have a more active role in their death and allowed them to ponder the meaning of what it meant to die well. In general, a good death meant dying with the help of family and community. The view reflected the vision that a “good death was the result of a life well lived” (1).

Aristotle, the prominent Western and Greek philosopher during this time, corroborates this viewpoint. For him, a good life is one that is complete, and “the complete is what is chosen always for itself and never on account of anything else” (2). Consequently, the human life is good only

if it is viewed from a holistic view: a brief time of goodness or happiness is not enough to have led a good and complete life. Aristotle believed that the human life and “the human good comes to be disclosed as being-at-work of the soul in accordance with virtue” (2). A good life, and, therefore, a good death, is one that is whole, complete, and lived in accordance with reason and virtue.

The Bhagavad Gita, an ancient South Asian text written at some point between 400 BCE-200 CE, is not far off from this theme (3). Though this is an influential Eastern text, it still has a common theme associated with the era, as well as with the viewpoint of other prominent figures around the world. The Gita questions how we can live a spiritually meaningful life through the teachings of Lord Krishna and his conversation with Arjuna, leader of the Pandavas. As stated in the Gita, life is not just what is on earth, but what transcends after it. Like Aristotle, the Gita shows that a good and complete life is a continuation of one’s physical life here on earth: whether it is by future kin, according to Aristotle; or by a non-material existence, according to Lord Krishna. Krishna teaches in the Gita that, “Whoever, at the end of his life, quits his body remembering Me alone at once attains My nature. Of this there is no doubt” (4). Achieving Krishna consciousness, or transcendence and oneness with the Lord is important at death, but for a pure soul and to have lived a good life means that one should practice this consciousness and remembrance from the very beginning of life. Again, having lived a virtuous and pure life is what leads to a good death.

While people may believe that Eastern and

Western ideas and lifestyles are opposites, both of their conceptions on death and dying are not so far off from each other. Not only do Aristotle and the Bhagavad Gita have a lot in common on this subject, but St. Augustine also has a similar view on death and dying. In St. Augustine's *City of God*, the same principle of life transcending an earthly life is referenced, as it is in the Gita. Therefore, by emphasizing a life without materiality and placing significance on the afterlife, Augustine states that we should not be concerned with how we will die. Whether you are wealthy and lead a more lavish life, or if you are poor but are good and one with God, death is inevitable and it will not have mattered how you led your life with material and earthly possessions when you are faced with death. Saint Robert Bellarmine furthers this idea in his work, *The Art of Dying*. St. Bellarmine believed in an essential spiritual aspect of dying well, and wanted to incorporate the process of dying into living. He believed that death produced by sin is evil, yet can bring you blessings such as ending miseries of life. He was characteristically known for his belief that if you want to die well, you must live well by loving God and living a simple, pure life. By furthering that a good death is not only a part of dying, but also a large part of life and living, St. Bellarmine echoed the sentiments that previous figures and texts furthered in this era.

Death and dying during the Historical-Modern Time (the 16th to 20th centuries), were perceived differently due to the rapid development of healthcare and technological advancements. The main sentiment on death in this era was that dying a good death was not characteristically determined by living a good life. Instead, a good death was one that was well-managed by healthcare professionals and medical protocols. It also included involvement of the patient with the other medical professionals when discussing plans of action and management of various aspects of dying, a way to inform the patient about their probable future. However, when death did occur, it was not viewed as a natural part of life, but rather as a failure that could have been avoided.

Currently, in the Post-Modern Time (from the 1950s onwards), there has been a change in awareness and values regarding death and dying. The process became an "open awareness, when both patient and healthcare professionals knew that the patient was dying and the dying process was made transparent" (1). The change in what constituted a good death was not only implicit, but was also reflected by the change in definition by

the Institute of Medicine: "decent or good death is one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards". To die a good death meant to end with the least amount of suffering for both the patient and their loved ones, all while considering other areas of life that are important to the patient. This complex understanding of what meant to die a good death led to the rise of palliative care and hospice movements, starting with the opening of St. Christopher's Hospice in 1967 in London, England. Elizabeth Kübler-Ross, psychiatrist and pioneer in palliative care and hospice care, furthered this movement by developing and explaining the famous stages of dying, as well as coming up with ways to help terminally ill patients make peace with the natural process of death. The World Health Organization then expanded the definition of palliative care to be an interdisciplinary way to improve quality of life for both patients and their families so that they are able to make peace with their death. By helping medically, physically, emotionally, psychologically, and spiritually, healthcare professionals can ease the hardships and thoughts associated with death and dying and can help individuals die a good death.

While each period has distinct features on what it means to die a good death, all of them play a role in painting an accurate picture on what it actually means to die a good death. Yet presently, while there is an emergence of palliative and end-of-life care and holistic ways to approach dying a good death, there is still a persisting tension between ending life well and prolonging it. A good death does not only encompass the dying moment, but also the life a person led before this turning point. What exactly does dying a good death entail? To pursue these matters, I will first be examining what contributes to a good death. With examples from Wendell Berry's *Hannah Coulter*, Leo Tolstoy's *The Death of Ivan Ilyich*, Robert Martensen's *A Life Worth Living*, and Elizabeth Kübler-Ross's *On Death and Dying*, among other novels and scientific papers, I will determine various distinct areas that play a role in what it takes to die a good death. Examples of characters, as well as real life patients, who have been in positions where they have had to grapple with facing death, will guide me in determining these areas.

One prominent character that I will be analyzing is Nathan Coulter from Wendell Berry's

Hannah Coulter. Nathan lived his life in the rural town of Port William, Kentucky, where he grew up, got married, and worked all his life. He was an avid farmer and loved to be close to nature. These things do not change when he was diagnosed with terminal cancer. Though Nathan knew he was sick, he did not go to the doctor until his family urged him to go. He had lost weight and was often unable to get out of bed, yet he tried to work it off by spending time in the field. Once he accepted his death—the final stage of Kübler-Ross’s stages of grief—he did not fight it and he did not try to change his outcome. To Nathan, dying a good death meant culminating your life with meaning and appreciation of what you experienced and cherished throughout it. Dying a good death meant not only living a good life, but it also meant spending the last moments with people you love as well as doing things you love. Dying was not meant to be prolonged, but accepted. This was not in the spirit of resignation, however. Nathan’s acceptance of his death was characterized by fulfillment of his life and peace of what had to come.

Nathan is a good example of what it means to die a good death for some people. While all of his end-of-life decisions may not be accepted today, such as his refusal of any medical interventions, I believe that Nathan Coulter is a prime example of what it means to die a good death. I will be referring to him while delineating certain aspects of what I have found to constitute a good death through analyzing various novels, scientific papers, and real-life stories. His experience will also shed light on what a potentially bad death could look like.

In the second part of my thesis, I will look at the phenomenon of dying an early death in its most extreme and uncomfortable form, the death of a child. The death of a child is unnatural and heartbreaking. It raises many philosophical questions for family members and healthcare professionals, as well as for the child itself. How can we explain death and dying to a child? Do we have any responsibilities when it comes to end-of-life care for a child? Are there any additional aspects we need to take into consideration if a child is terminally ill or has passed away? How does it feel to outlive a child? How are family members affected? I will primarily be utilizing Flannery O’Connor’s *Death of a Child* and scientific papers on end-of-life care and special considerations for a dying child to understand this issue. I will also be referencing Virgil, another character in *Hannah Coulter*, whose death parallels the death of a child. While Virgil, Hannah’s first husband, was a young

man, he died an untimely death at war. Virgil’s incomplete life without a natural end brought grief that extended his self and encapsulated both his family and his community back at Port William. Hannah felt as if the grief for him was also grief for her, a form of devastation and self-pity that is a common feeling when a child passes away.

Lastly, through scientific papers and personal interviews with healthcare professionals, I will utilize the third and last part of my thesis to understand what a variety of healthcare professionals are currently implementing so that patients have a comfortable and good death, as well as what these professionals seem to be lacking in this realm. I also wish to understand how these professionals deal with something so vulnerable without letting it take over their lives. Delineating these experiences may be a way for healthcare professionals to integrate this analysis into practice so that patients facing death are able to have a “good” dying process and so that individuals helping the patient out also receive the mental and emotional support they need.

This paper will not focus on patients without cognitive faculties or on the issue of passive and active euthanasia. Due to the limited scope of my thesis, I will focus more on the philosophy and literature of dying in people who are able to play an active role in their dying process and do not have a sudden death. In this thesis, I hope to shed light on the various distinct aspects that make up dying a good death, and how this applies to children. By listening to the stories and findings of authors, researchers, families, healthcare professionals, and patients, both young and old, I hope to understand what it truly means to die a good death.

Part 1.1: The Role of Life in Death: A Case Study Between Nathan Coulter and Ivan Ilyich

In the first part of my thesis, I will be examining what it takes and means to die a good death. I will begin this section with a case study of two prominent fictional characters: Nathan Coulter from Wendell Berry’s *Hannah Coulter* and Ivan Ilyich from Leo Tolstoy’s *The Death of Ivan Ilyich*. While Nathan Coulter integrated and stressed community, family, and work into his life, Ivan Ilyich was devoid of these aspects of life, and was mainly concerned with his social status, others’ perceptions of him, and his superficial interactions with the elite. While these two characters lead unique lives and put an emphasis on different things, they both have much to shed light on when

it comes to dying a good death.

Wendell Berry's *Hannah Coulter* takes place in the rural town of Port William, Kentucky and narrates lives and deaths with remarkable lucidity. There, a close-knit community of people including Hannah Coulter—the novel's protagonist and narrator—cannot imagine a life without each other. Hannah recounts her major life events, such as her marriage with her first husband, Virgil, who dies an early and unexpected death in World War II, leaving her and her baby behind. Hannah then marries Nathan Coulter, who has enriched her, her family, and her community's life in many ways. Hannah writes this story as a memoir, to look back at her life and admire how beautiful it was. It is a way for her to express gratitude for the love, memories, heartache, and dependence she had with the people in her town and her world.

Hannah's husband, Nathan Coulter, crafted a good life that showed he was resilient and selfless: traits that stayed with him even after was diagnosed with terminal cancer. Nathan was a quiet man who had fought in the war, but came back to his hometown of Port William soon after. Nathan was a hardworking man: he repaired his estate at Cuthbert place, where he also started a farm for himself and his community. Nathan was a generous man: he took care of Virgil's family though he did not need to. All he knew was that two parents lost their only child in an untimely death and they needed love and help, just like anyone would. But most importantly, Nathan was a loving man. He loved his wife, his children, and his home. He led a long and fulfilling life until he started to get ill and people could tell that his condition was deteriorating. Berry described his state with a familiar description:

Nathan was sick, and he knew it, he knew it better than I thought he did, a long time before he consented to go to the doctor. He was wearing out, he said, but he wasn't only wearing out, he was sick. He lost weight and strength. He got bony and hollow-cheeked and hollow-eyed. You could see his skull behind his face. He felt bad. He was often almost too ill to get out of bed. But he kept on in his old way, quiet, more pleasant even than usual, staying busy off someplace, mostly by himself (5).

But Nathan knew he was sick and did not want to go to a doctor: he only went for his family's sake,

another manifestation of the love and regard he held for his wife and family. The doctor explained to him that he had an advanced and inoperable cancer that was spreading over time. For Nathan, the cancer was incurable and he did not want to undergo any treatment to prolong his life. Death was his only option.

With surety that he had lived a whole and complete life, Nathan knew how he wanted to approach his terminal diagnosis; he was certain that with acceptance of the future and with his family by his side, he would be able to die a better death. Though he had physical pain, Nathan lived with his diagnosis with a few important things in mind. He knew he had the things and people that mattered to him during his last days. He knew he lived his life well. He knew he did not want any interference of medical technology or prompt treatment as the doctor offered. Nathan wanted to die a natural death, happy without any unnatural ways to extend his life. His wife, Hannah, described his last few days as one where they were just "living right on [, which] called for nothing out of the ordinary. We made no changes. We only accepted the changed as they came" (5). After his diagnosis, "he did [not] last long after that. Death had become his friend. They say that people, if they want to, can let themselves slip away when the time comes. I think that [is] what Nathan did he was not false or greedy. When the time came to go, he went" (5). Nathan knew how he wanted to die: he did not want technology to artificially prolong his life. He just wanted to spend the last part of his life with his family and his work. Nathan was fully cognizant of what was to happen, and he knew that, to achieve a good death, he would have to continue to live a simple and pure life, what he and Hannah referred to as 'living right on.'

On the other hand, Leo Tolstoy's *The Death of Ivan Ilyich* portrays a vain life that unfortunately leads to a worse dying experience. The novel opens with a scene where Ivan Ilyich's colleagues are discussing his death, his upcoming funeral, and how much of a hassle it would be to visit Ilyich's grieving widow. Tolstoy then recounts Ilyich's shallow life, one where he is hungry for a higher social position as well as for social acceptance, through fake encounters and indulgence in materialistically pleasurable interactions. After Ilyich is diagnosed with a terminal illness and is bedridden, he is tormented by the pain and suffering he must go through, and he is maddened when no one gives him attention. He is afraid of death and only on his deathbed, when he has no

choice but to face his death, does he realize that he did his life all wrong. When faced with dying, he fears: “what if my entire life, my entire conscious life, simply was *not the real thing*?” (6). He had no true relationship with his wife and children, and only towards the end of his life does he start to form a connection with his servant, Gerasim, and his son, Vasya. He needs to reconcile the realization that he has lived an artificial life just a few moments before his death.

Tolstoy describes Ilyich’s life as the most “simple and commonplace—and most horrifying,” a life that is, arguably, not well lived (6). Ilyich’s life may have had social and material wealth, with various legal positions such as examining magistrate, but it did not have wealth in values, relationships, and the self. These aspects contribute to Ilyich living an insufficient life, which comes to haunt him at the time of his death. Ilyich was not able to form a relationship with his family, counter to Nathan Coulter. Tolstoy describes Ilyich’s struggling family life: “his father and brothers, and especially their wives, not only hated meeting him, but unless compelled to do otherwise, managed to forget his existence” (6). Ilyich also did immoral things to achieve status but did not feel bad about it because people in high standing never seemed to bother with it either. Tolstoy describes that, “as a student he had done things which, at the time, seemed to him extremely vile and made him feel disgusted with himself; but later, seeing that people of high standing had no qualms about doing these things, he was not quite able to consider them good but managed to dismiss them and not feel the least perturbed when he recalled them” (6). Consequently, Ilyich lost much of his moral compass because he noticed that people in higher classes were doing corrupt things and did not feel bad about them, so why should he? Ilyich did not even marry his wife because he loved her. Instead, “in acquiring such a wife he did something that gave him pleasure and, at the same time, did what people of the highest standing considered correct. And so Ivan Ilyich got married” (6). Overall, Ilyich did not lead a reflective and honest life until nearing his death.

Ilyich’s inadequate mode of living permeates into his dying process, as he is not treated well by most people after his condition starts to deteriorate, ranging from doctors to even his own family. After feeling pain in abdomen, Ilyich’s doctor “dealt with him in precisely the manner he dealt with men on trial,” in a superfluous manner and very methodically (6). Doctors said he either had a

floating kidney or a disease of the caecum. Ilyich went to celebrated doctors and even alternative medicine therapies, like homeopathy, but he lost faith in everything because he had no relief from his pain. He soon began to be aware of his death: “there was no deceiving himself: something new and dreadful was happening to him, something of such vast importance that nothing in his life could compare with it. And he alone was aware of this” (6). The rest of his death continued to torment him, without anyone to understand him until the very end of his life. Because of his lack of introspection and fulfillment in his life and his relationships, it was hard for him to cope with death, contrary to Nathan Coulter. Ilyich’s gruesome pain and confrontation with death is described throughout the novel:

And suddenly it flashed through the screen and he saw it. It had only appeared as a flash, so he hoped it would disappear, but involuntarily he became aware of his side: the pain was still there gnawing away at him and he could no longer forget—it was staring at him distinctly from behind the plants. What was the point of it all [...] He went to his study, lay down, and once again was left alone with it. Face to face with it, unable to do anything with it. Simply look at it and grow numb with horror. (6)

When you are dying, you begin to think about your life, how you could have been a better person or friend, or you could have done things differently. Ivan faces these predicaments once he has to live with the pain and suffering, and he is conflicted with what he can do at this time to rectify his past.

While Ilyich struggled with his death and with these issues, towards the very end of his life, he found comfort in his suffering while dying. Therefore, while he did not have a meaningful life, he did eventually die a good and fulfilling death. Ilyich talks to his butler, Gerasim, who tells him that caring for Ilyich is not an unpleasant experience, it is a part of life: “why should I [not] help you? You [are] a sick man” (6). It is at this moment where Ivan realizes that not everything is done for a reason or for a benefit. He helps because this man is sick. He says, “Gerasim was the only one who did not lie; everything he did show that he alone understood what was happening, so no need to conceal it, and simply pitied his feeble, wasted master” (6). At this point, Ilyich repented

his actions and how he treated other people in his life. Without the company of his son and Gerasim while he was dying, he may not have realized this. The time that they spent with them might have made him realize the value of feeling love and support, how important that is, and how much that supersedes money or social status.

After his son and Gerasim's companionship and altruism, Ilyich reverted into someone who wanted a different type of wealth that he was not used to: the wealth of good and quality relationships, love, and true friendship. Tolstoy writes, "He wanted to be caressed, kissed, cried over, a sick children are caressed and comforted" (6). When he thought about his past he realized that what he thought was happy and pleasant might not have been what it really was. It all seemed different than how he thought of it before. He did not have anyone with which to experience happiness. While living a good life may have helped Ilyich face death in a different light, he did not need to live a good life to die a good death. Though late, he rectified his mistakes and found someone who would love him and care for him in his last days. And that is when he realized: "Where was death? What death? There is no fear because there was no death. Instead of that there was light" (6). There was nothing for Ilyich to be afraid of when faced with death because he had been forgiven and he had come to a realization about what really mattered. This realization transcended his pain, suffering, and fear of death.

Ivan Ilyich had a radically different view about his impending death as compared to Nathan Coulter. While Nathan made peace with his diagnosis and prognosis, Ilyich denied his death and suffered until his final realizations, just moments before his death. Though Nathan Coulter and Ivan Ilyich lead different lives, I do believe that they ultimately die good deaths. Factors such as awareness of death and dying, emotional support from loved ones, choice and control over medical treatment, and satisfaction with one's life in general are just some ways to help a person die a good death. Such factors will be analyzed in the following section.

Part 1.2: Factors in Dying a Good Death: Ways to Help Facilitate a Better End of Life

In the previous section of this thesis, Ivan Ilyich from Leo Tolstoy's *The Death of Ivan Ilyich*, and Nathan Coulter from Wendell Berry's *Hannah Coulter*, led very different lives but they both died a good death in their own respects. When analyzing

the two characters in the case study, specific factors were determined as helpful to aid in dying a good death. Not all factors are necessary in dying a good death, but they include pain and symptom management; patient dignity and autonomy; clear communication by healthcare professionals; stages of grief and eventual awareness and acceptance of death; emotional support and family presence; satisfaction with life; spirituality and religion; and where to die and last wishes. These factors will be analyzed in this section in no particular order of priority.

Pain and Symptom Management

Before a dying patient is able think about philosophical questions of life and death, it is important to be able to manage the physical pain they are experiencing. Looking back at a previous literary example, Ivan Ilyich was in a tremendous amount of physical pain. At that time, doctors were not aware of his exact diagnosis, and the medicine he received was not for treatment, but was there to alleviate his physical pain. Tolstoy recounts how much the medicine helped Ivan Ilyich during this time:

[Ivan] remembered his medicine, raised himself, took it, then lay on his back observing what a beneficial effect the medicine was having, how it was killing the pain. Only I must take it regularly and avoid anything that could have a bad effect on me. I feel somewhat better already, much better (6).

He began probing his side—it was not painful to the touch. "I really can't feel anything there, it [is] much better already. He put out the candle and lay on his side—his caecum was improving, absorbing"(6). When Ilyich's physical pain was not manageable, he was not able to properly address the emotional and psychological parts of life with attention and care:

"The pain in his side exhausted him, never let up, seemed to get worse all the time; the taste in his mouth became more and more peculiar; he felt his breath had a foul odor; his appetite diminished and he kept losing his strength. There was no deceiving himself: something new and dreadful was happening to him, something of such vast importance that nothing in his life could compare with it. And he alone was aware of this" (6).

Without any pain management, Ivan was often frustrated with his pain and was not able to work through other aspects of his illness with a clear mind. Yet, after he could manage and control it, it was easier for him to think about other things on his mind, such as his superficial relationships and his loneliness. This is applicable to many real-life instances, where a person dealing with death is so occupied with the physical pain that they are not able to focus on other things that could help ease their pain and bring them happiness. Once physical pain can be controlled in an optimal way, then additional steps for good medical care during the end of life can be initiated, such as instating advanced directives or a do not resuscitate order, having proper care with enough nurses and doctors, and having a surrogate decision maker designated by the patient (1).

Pain management is important to address because there have been certain instances where pain causes patients to be alone or away from people, who they might otherwise need to cope with their death. In Elisabeth Kübler-Ross's *On Death and Dying*, a doctor asks a patient why loneliness is so dreadful to him, and the patient responds by saying that he does not mind being lonely because sometimes it is necessary, but when being lonely and being alone become synonymous, that is when he has the courage to do something about the terrible pain he feels so he can change his state. The patient says:

I think, no, I do [not] think I dread loneliness because there are times when I need to be alone. I do [not] mean this. But unless I connect it with being abandoned in this situation, I [am] not going to be able to help myself. It would be okay if I felt alone, it [is] the torture that pain can give you, like you just want to tear your hair out. You do [not] care if you do [not] bathe for days because it [is] just so much effort, like you [are] becom[ing] less [of] a human being (7).

The pain causes anguish, and that causes a person to want something or someone there to combat that, especially when the person is terminally ill.

It is also important to know when a person receiving curative care for their pain should consider palliative care or hospice care instead. Palliative care, as described in the introduction, is an interdisciplinary way to improve the quality of

life for patients with serious illnesses, where death can be a possibility. Palliative care is appropriate in any serious illness, while hospice care, a type of palliative care, is specifically for the terminally ill. There may be a medical treatment or procedure while a person is on palliative care that can cure them, but this is not the case for hospice care, where the patient's condition cannot be cured, and they must turn to comfort and support instead (8). Curative treatment from an illness is important, but when an illness becomes more permanent in a person's life, it is important to take further steps. This is when a palliative care team and/or hospice care is called on to support a patient and improve their quality of life (9).

The rise of treatment options such as occupational therapy (OT) is a notable example of how to improve the quality of life of people with life-threatening diseases, a critical aim of palliative care. From semi-structured interviews in both inpatient and outpatient sectors of occupational therapists and researchers qualitatively found that occupational therapy—which promotes health and well-being through occupation—provides comfort and safety and also relies heavily on trusting the occupational therapist to know what is needed for the patient (10). There have been endless stories about how occupational therapy brings routine back into the lives of people who are struggling to come to terms with their current situation and preoccupy their minds with healthier thoughts and hobbies. One such patient, Michelle, recounts her success story with OT: “When I first came here I thought I [am] never going to be able to use the needle again [for dressmaking] ... now I can!” Michelle's quality of life has improved significantly through occupational therapy: “I did [not] want to live, but now I can see things can come back to normal” (10). Another patient, Oliver, was paraplegic because of a spinal cord compression. With the help of his occupational therapist, he was able to work on transportation and transfer techniques with a specialized chair made for him: “It [is] good to be out of the room... [it is] too small [and] most of my friends and family will be here...so it [is] good to be out in the open” (10). Of course, occupational therapy is not the only subset of palliative care that can have concrete positive change on the lives of those who are facing the end of life. Just as Nathan Coulter relied on his occupation and work to get his mind off his terminal diagnosis, and was able to use it as a healthy escape, many other people facing end-of-life issues are able to do so through OT.

Patient Dignity and Autonomy

Man does not die when his breath is taken away; he dies when his dignity is taken away. When dealing with a life-threatening and/or terminal disease, it is important for a patient to be able to make decisions for themselves about their course of action and have a say in their treatment options. It is also important for a patient to preserve their dignity while doing so.

First, it is important to clarify the assumption that if a patient were able to make decisions for themselves, then they would do so with their dignity in mind. This is not always the case. There should be a balance between a patient being an autonomous individual who can make their own decisions and a patient who wants to preserve their dignity while doing so. Because of the rise of technology and use of various ways to prolong life, a patient's dignity can be compromised, even by the patient's own choice. When it comes to dealing with the concept of dignity, Physician L. Balducci explains that, "To die with dignity" was already a common slogan, but dignity was referred mainly to some objective findings that included unnecessary intrusion into a person's body (respirators, catheters, intravenous lines), as well as cleanliness and freedom from discomfort" (11). Balducci recounts a story of a patient, Mr. Jones, who, like many patients, is confused by the advanced scientific jargon about their disease and diagnosis. Balducci explains that:

Mr. Jones craved clarity. Confused by my talk of 'cancer progression' he wanted to know how long he had to live and why he was wasting his scarce and precious time in the hospital if no more treatment was planned. He did not know how to ask the proper question and he was obviously scared to antagonize the doctor and the healthcare team. This confusion affected his demeanor and his countenance. He felt like a man carried adrift by a current without goal or destination. When I leveled with him and communicated to him his prognosis in terms he could understand, he got hold of his life again: he knew what to expect and what to plan for (11).

Balducci explains that by properly wording Mr. Jones' prognosis and by thinking ahead for the patient, who may be hesitant to ask questions

openly and possibly offend healthcare professionals unintentionally, he was able to re-institute to Mr. Jones his dignity. Balducci refers to this dignity as the patient's ability to run their own life to their liking, even if there may be limited choices and options than before. The word dignity derives from the Latin word 'dignus' which translates to 'worthy.' Because Balducci was able to give control to Mr. Jones, regardless of his brutal diagnosis, he was able to restore the worth and dignity the patient deserves. Balducci beautifully explains the meaning of dignity, as learned by his interaction with his patients:

Mr. Jones taught me that the medical system may deprive a person of his/her dignity when it deprives a person of the ownership over his/her disease. The source of the patient's dignity is the restoration of this ownership to its fullness. The external aspects of death are important because they reflect this interior condition of ownership that we may want to call 'spiritual' (11).

Therefore, dignity is embedded in patient autonomy because it is important to involve the patients in their own medical care. An important way to ensure a good death is to not only physically control pain and other symptoms, but also when "patients and family recognize death as a unique living experience to be treasured as any other living experience. A death with dignity brings healing, that is always possible even when cure is out of reach" (11). Even if the patient and the practitioner may not see eye to eye on controversial issues such as euthanasia or artificial life support, it is important to have both of them engage in honest conversations and open discussions to find an option that is best for them (11). Looking back at Nathan Coulter's example, his dignity was preserved because he took ownership in his further course of treatment, or lack thereof. The physician personally recommended a rigorous treatment option, but still respected Nathan's decision of refraining from anything and focusing on himself, his family, and his work instead. Hannah recounts this experience:

The doctor went on to prescribe an intensive course of therapy, starting with radiation. It was a story we all knew, one that has been lived and told too many times in Port William, a bad story. But

I was surprised when Nathan, without exactly interrupting, stood up. He had come to the end of his submission, though not of his patience or his quietness. He put out his hand, which the doctor a little wonderingly shook. Nathan said, “Thank you, doctor. Thank you for all you [have] done (5).

Therefore, with dignity often comes the respect for a patient to make their own choices and preserve their autonomy. Just as we saw with Nathan’s example, Balducci explains that “the first role is to establish how a patient wishes that [their] death be managed. That defines the conditions in which each patient wishes that any form of intrusive life-supporting treatment be instituted, continued or withdrawn” (11). Ideally, Balducci suggests that open communication should occur before the patient’s death is impending by a healthcare practitioner who has rapport with the patient. He suggests this approach would avoid any sudden and ardent emotions and reactions that can be felt if death is imminent.

With the rise of modern technology comes what Physician and Ethicist Robert Martensen calls a “cornucopia of choices:” an array of choices for patient treatment (12). Martensen suggests that we are used to the thinking that having more of something is better, but if we stray away from this thinking:

If, strange as it seems, *more is not better*, how should one go about making individual choices? The first thing to realize—and it is also counterintuitive—is that an individual’s preference for one approach over another is not as *individual* as one might think (12).

He goes on to say that end-of-life care choices not only involve various other parties, both personal and professional, but also that the option of choices provided to the patient is often what local specialists are used to doing. Because “each proceduralist develops a procedural ‘signature,’” a lot of what is done regularly by the specific healthcare professional is offered to patients as a course of treatment according to the Dartmouth Atlas data (12). This can compromise a patient’s autonomy in the practice because there is a narrower array of choices that is presented to the patient experiencing end-of-life care. Martensen does acknowledge that there currently has been a recent development of patient-oriented decision

aids that help decipher between the various treatment options. Some studies have shown that “truly informed patients with chronic problems who are offered a choice between conservative or invasive approaches tend to prefer the former” (Martensen, *A Life Worth Living: A Doctor’s Reflections on Illness in a High-Tech Era*). In our current society, it is important to be respectful of the patient’s choice especially because there are so many options that they have. If the patient has the choices properly and openly communicated with them, then they will be able to have a more active role in the dying process.

To end this section, I would like to briefly examine the case of Ivan Ilyich and how he was not at all involved in his case and was not given dignity or autonomy by his healthcare professionals. Ilyich was confused about what his unknown condition meant to him and the rest of his life:

To Ivan Ilyich only one question mattered: was his condition serious or not? But the doctor ignored this inappropriate question. From his point of view it was an idle question and not worth considering. One simply had to weigh the alternatives: a floating kidney, chronic catarrh, or a disease of the caecum [...] but then it appeared that there was some confusion between the results of the analysis and what should have followed from it. It was impossible to get any information out of the doctor, but somehow things were not working out as he had said they should. Either the doctor had overlooked something, or lied, or concealed something from him. Nonetheless, Ivan Ilyich followed his instructions explicitly and at first derived some comfort from this (6).

Ilyich’s doctor did not pay attention to his concerns, nor did he even attempt to placate Ilyich’s fears. While this may be an extreme example, there are cases where healthcare professionals lack communication with the patient, which can lead to a lot of distress for the patient, who is already going through so many thoughts on end-of-life care.

Clear Communication

As touched upon in the last section, once the patient knows the approach they want to take and has a say in their end-of-life care, it is very important for the healthcare professional to have

open and clear communication with the patient. However, it is equally as important for healthcare professionals to communicate well with each other and with the patient's loved ones to ensure that everyone is on the same page because a good death often involves more than just the person who is dying. Unfortunately, with all the commotion and high intensity in a hospital setting, individual patients may feel as if they are not getting the care they deserve, and patients and their families often feel as if they have to take on the burden of this end-of-life care on themselves.

An important form of communication is talking to the healthcare professional in a way that is understandable to the patient. A study done in Taiwan found:

The care team should know the extent to which the patient understands his or her own illness, choosing an appropriate timing in a quiet environment. Someone who the patient fully trusts should conduct the meeting, and should proceed in a guiding, exploring, and progressive manner. The care team should keep the principles of mutual trust, autonomy, confidentiality, and beneficence at the forefront of their minds. They should listen carefully to the questions the patient raises and encourage the patient to release his or her emotions. It is important to let the patient know the future care plan, and assure him or her that the care team would never abandon and will accompany him or her until the end. Truth-telling has to be individualized, especially to the elderly (13).

Martensen promotes this view as well, encouraging physicians to slow down and consider all possible indications first. The doctor has years of training and immersion on terminology and implications, but what about regular, ordinary people? By interacting with terminally ill patients in a way that can help them come to terms with their diagnosis in an easier way, healthcare professionals have an important responsibility on them (12). Elizabeth Kübler-Ross's *On Death and Dying* features real-life stories of patients going through end-of-life care. In a doctor-patient interview, the patient said:

Oh, I think, I feel that, I wish that my doctors could explain a little more to me. I realize, I mean I still feel like I'm in the

dark, as far as really knowing about. Well, now maybe there are some people who want to know how sick they are and some people that don't. Well, if I thought that I just had a short time to live I would want to know that (7).

When the person asked why the patient didn't ask the doctors, the patient said that the "doctors are always in a hurry" (7). When healthcare professionals are doing their job continuously, it is probable for some to not have as much of an intimate connection with their patients, which can cause the patients to feel hesitant about asking about their diagnosis and prognosis. Another patient recounts an experience about not wanting to bother hospital personnel since they are so busy:

I mean [I am] sometimes in intense pain and things like that. I do [not] bother the nurses in the sense that I ask for anything I can do myself, which has often made me feel that they are [not] aware of how I really feel. Because they do [not] come in and ask. I mean I could have really used a backrub, really, but you see, they do [not] come in to me routinely and do what they do for other patients that they think are ill. [...] I do everything else for myself even when I have to do it slowly and sometimes I do it in pain. I think this is all good for me. But because of this they do [not], I do [not] think they really—I think for hours on end, I think someday if I ever started bleeding or going into shock it would be the cleaning lady that found me, not the staff. Because they just come in, you get a pill, and I get a pill two times a day unless I ask for a pain pill [...] I think they should be aware of how their patients are (7).

This is an unfortunate experience; even if it is one that is infrequent, for it is unfair that a patient who does not have much time left should feel invisible. It is a good way to understand how healthcare professionals should openly communicate with their patients so that they feel heard and cared for.

Robert Martensen brings up another real-life example of a woman named Marguerite, who was not able to voice her concerns to her healthcare team and eventually lost her life due to the lack of communication. Marguerite was going to try

a bone marrow transplantation (BMT) and high-dose chemotherapy (HDT) for her inflammatory breast cancer. She was not treated well by her doctors because they did “not make a point of knowing what mattered to her and adjust their trials accordingly” (12). Martensen believes that if she stated her existential priorities in a timely and forceful manner, then he believes that, maybe, her team of healthcare professionals would have had a different involvement in her care, especially in her final months. He believes that it was her compliance, her lack of a strong voice, her suppression of her inner sense that could have been afraid in an alien environment that played a role in her harsh death. When a patient is not able to voice their concerns because of timidity or trepidation, some of the responsibility lies on healthcare professionals to pick up on these cues and do their best to make the patient feel heard and cared for.

Late neurosurgeon Paul Kalanithi says that it was his job as a physician to advocate for his patient if the patients could not do it for themselves. In a specific instance, Kalanithi had to witness a patient having a long and painful treatment that may not have been successful. In this circumstance, he:

[A]cted not, as [he] most often did, as death's enemy, but as its ambassador. [He] had to help those families understand that the person they knew—the full, vital independent human—now lived only in the past and that [he] needed their input to understand what sort of future he or she would want: an easy death or to be strung between bags of fluids going in, others coming out, to persist despite being able to struggle (14).

Robert Martensen recounts an experience with his dying father, who had a similar story. Martensen describes the death of his father, where he had to make a conscious decision as a physician and family member, to alleviate his pain because that was the best for his father at that time:

All the family who were there could spend time with dad and have a chance to say goodbye, and, um, he was getting morphine [...] still conscious, we said you know, dad, I said... dad, you know, this is, life is slipping away, I think it [is] your time...I'm going to take the oxygen off... and then he said thank you, and he died two or three minutes later (12).

Communicating properly is essential to remove unnecessary burden from the patient, who already

has to consider many things during this time.

With the adoption of the palliative care model, there is hope for increased involvement and open communication between all parties involved in the patient's end-of-life care:

It [is] about when one learns when one has one of these diagnoses...where a disease may shorten life... to start planning from the beginning [...] with the physicians, a kind of interactive exchange of forming a treatment plan together, so that it is [not] just we can do this, we can do this ... consultation between the patient and the patient's family is a regular process where everybody is kept in the loop. I would love to see hospitals embrace that, particularly the multispecialty academic medical centers [...] they tend not to do it, the specialists do [not] seem to provide coordinated care [...] nothing is sustained [...] and the result is that people think that things are just done to them (12).

Many stories have expressed that there has not been adequate communication between healthcare professionals and specialists. Many times, tests are repeated, and it is often the responsibility of the patients and their families to update each specialist with the correct paperwork and test results on what the other did. This can cause an added stress on the family to make sure each healthcare professional is on the same page as the other, and can also cause the patient to feel dehumanized and unheard in their own end-of-life process.

Not only is it important for the patient and the doctors to understand and communicate with each other, but it is also important for loved ones to be properly involved in the process. Martensen talks about Betsy, who already told her family that, in no circumstance, did she want to live her life “like a vegetable” (12). Betsy eventually sank into a coma after her initial diagnosis of pneumonia, but the “ICU's chief neurologist continued to report that she was doing ‘well’ or if she made some reflexive twitch, that she was doing ‘better’” (12). Betsy's condition did not change after a few weeks, and Betsy's sons later realized that the doctor was known to insist that there would never be a loss on his end. The doctor insisted that he knew better for his patient, but was only doing things for his own intentions. He was not truthful to Betsy's family, and thereby disrespected Betsy's end-of-life wishes. Not only was this a violation of patient autonomy,

but it was also an unclear communication between the doctor and the patient's loved ones. Betsy's lawyer obtained a second neurological opinion, where the doctor said that she would never recover any significant function. Betsy got a second infection before her oldest son decided to stop any additional treatment. That caused her to die shortly after. While her initial hesitation to be admitted to the hospital may have caused her condition to be much worse, Martensen questioned:

Would things have gone differently for her and her children, would she have avoided the degradation of an extended demise and they a catastrophic rupture, if her ICU doctors, especially her first neurologist, had reached agreement earlier on her prognosis? [...] Had Betsy's medical team provided a univocal assessment of her situation, her sons, though divided, might have been able to come together in grief as they respected her wishes and let their mother go. Instead, as often happens when family members quarrel around the bed of a member who has entered death's penumbra, division among the doctors amplified preexisting division in the family (12).

The importance of clear communication cannot be undermined, especially in situations such as this one. If healthcare professionals could talk to each other and understand where they are in the patient's end-of-life care, come to agreement on their future course of action, and keep the patient and their loved ones in the mix, then the dying process would be less stressful and complicated.

Stages of Grief & Eventual Acceptance of Death

Elisabeth Kübler-Ross, psychiatrist and groundbreaking author of *On Death and Dying*, revolutionized the Five Stages of Grief, a pattern of adjustment that people experiencing any sort of grief undergo. The five stages she centers her book around are denial, anger, bargaining, depression, and acceptance. Though her stages are not presented with tangible evidence through a scientific standpoint, her "stages" have merit. While I do not think that a patient has to necessarily experience these stages in a set order, I do believe that it is important to go through various emotions, both positive and negative, in order to understand

one's grief, and in this case, end of life, in a deeper and more transformative way.

In order to die a good death, I believe that we must feel these stages of grief—and it does not matter how long or short each feeling lasts—so we know that we have experienced many ways of dealing with death before making peace with the situation. Because we do not struggle with death and dying unless we or someone we know and love are experiencing death, we have to do a lot more introspection when we are faced with the situation than if we pondered it throughout our lives. Kathleen Dowling Singh eloquently expresses how we are programmed to run away from death, ignore the present situation, and latch onto an abstract concept in order to aid in this escape:

We all try to flee death. We attempt to run from our corruptible body and identify with the seemingly undying "idea" or "image" of our self. Although it is illusory, we are ingenious enough to manage for a time to have it be comforting. With this "idea" of our self, we catapult ourselves out of the present. The fear of death generates an intense sensation of time as fleeting, as finite we live on the run, greedily grabbing the next now, which we think preserves us. We live in fear of death, struggling to survive (15).

If we stop living in the fear of death and look at it as less of a struggle and more of a part of life, the adjusting to death will not be perceived as a burden.

Before acceptance of death, it is common for patients to go through many emotions, but the time that they spend in each stage depends on a case-by-case basis. Kübler-Ross goes through the five stages of denial and isolation, anger, bargaining, depression, and acceptance. She explains that the patient "will [first] feel the increasing isolation, the loss of interest on part of his doctor, the isolation and increasing hopelessness. He may rapidly deteriorate or fall into a deep depression from which he may not emerge unless someone is able to give him hope" (7). Denial allows people to collect themselves and come up with temporary defenses. However, the temporary shock will not last long and the numbness will disappear. Eventually, emotions like anger, rage, envy, and resentment can take over and that is difficult to cope with especially with family and staff (7). Kübler-Ross talks about how patients often bargain as an

attempt to postpone what is inevitable. It does not help when patients consider impending losses and anticipatory grief, where anxiety, depression, and grief flood a person who is about to face something potentially tragic. She explains that, to combat this:

Our initial reaction to sad people is usually to try to cheer them up, to tell them not to look at things so grimly or so hopelessly. We encourage them to look at the bright side of life, at all the colorful, positive things around them. [...] This can be a useful approach when dealing with the first type of depression in terminally ill patients (7).

She contrasts this more visible depression from another type of depression, which “is usually a silent one in contrast to the first type during which the patient has much to share and requires many verbal interactions and often active interventions on the part of people in many disciplines” (7). Kübler-Ross believes that the discrepancy between the patient’s readiness and the expectations from society cause a lot of grief and turmoil for the patient. She thinks that if healthcare professionals understand this conflict and articulate it to the patient’s loved ones, then patients will have some of their burden relieved from their shoulders. She thinks that “only patients who have been able to work through their anguish and anxieties are able to achieve this stage. If this reassurance could be shared with their families, they too could be spared much unnecessary anguish” (7). Once we get through those feelings, the patient eventually comes to the acceptance stage, which is not necessarily a stage where the patient is happier than before. This stage is characterized by the realization that death is an inevitable occurrence. Dowling Singh describes acceptance as a feeling:

[It is] centered in a very deep, very complete experience of disillusionment, even deeper than the disillusionment experienced during the phase of depression. Acceptance involves a thorough experience of that painful level, marked by remorse, regret, recognition of helplessness, and some outer stillness. The stage of acceptance is the acknowledgement that the sand is passing through the hourglass and the remaining grains are few. Acceptance is what the self does when denial is no longer possible (15).

Ivan Ilyich’s awareness of his death took plenty of thinking and introspection on his part, especially because he did not have help from his doctor or loved ones during this process. Ilyich eventually realized:

There was no deceiving himself: something new and dreadful was happening to him, something of such vast importance that nothing in his life could compare with it. And he alone was aware of this. Those about him either did not understand or did not wish to understand and though that nothing in the world had changed. It was precisely this which tormented Ivan Ilyich most of all. He saw that the people in his household—particularly his wife and daughter, who were caught up in a whirl of social activity—had no understanding of what was happening and were vexed with him for being so disconsolate and demanding, as though he were to blame (6).

It does not help that Ilyich has to go through this alone, but it is not surprising that this happens to him due to his past actions and way of life. By looking at Ivan Ilyich, that the stages of grief and understanding of death are better addressed and contemplated when the terminally ill patient has the choice of having support and guidance along the way, if opted for.

Emotional Support, Family Presence, Support for Family

While a patient is struggling with accepting death and figuring out what they want, their family, friends, and loved ones should help them out in whatever capacity is needed, from just being there physically to having a more active role. Loved ones should also get help because all of this is hard for them as well. This support makes a rough time more bearable and less intimidating for many parties involved.

Ivan Ilyich’s experience during his end-of-life care illustrates what loved ones should not do during this stage of life. Ilyich, as discussed earlier, did not have a strong connection to his family, which made it hard for him to cope with his death. For a majority of his dying process, he had to struggle with both the physical and emotional pain he experienced without the help of anyone close to him. If there was a deeper connection between Ilyich and his family and friends, then he

might have been able to approach his impending death with less resistance. Ilyich's wife constantly belittles his pain and says that he is fickle because he does not stick to the treatment that his doctor prescribes him. She does not take into consideration that the doctor has not been there to answer his medical questions, let alone be there for him as a personal resource. His daughter, too, was "strong, healthy, and obviously in love, she was impatient with illness, suffering, and death, which interfered with her happiness" (6). She was also not there for her father, though she very well knew that he may not have another day with her in the future. Ilyich not only lacks compassion from his family members but he also lacks compassion from his doctors. When he asks his doctor to alleviate the pain, the doctor says, "You sick people are always carrying on like this," as if it were some sort of excuse to him (6).

When a person is dying and suffering, it is not unusual for them to feel as if they are losing hope at certain points or situations of their end-of-life care. This possibility is completely ignored by both Ilyich's doctors and "loved ones," who think that:

[He] simply cannot adhere to the course of treatment prescribed for him. One day he takes his drops, sticks to his diet, and goes to bed on time. But if [someone doesn't] keep an eye on him, the next day he'll forget to take his medicine, eat sturgeon—which is forbidden—and sit up until one o'clock in the morning playing cards (6).

The people relationally close to Ilyich do not realize that he is grappling with various factors of his death: his physical pain, questions about his health and wellbeing, and concerns about his death and the unfamiliar process in general. Instead of being there for him, his family and friends let him face death alone. This did not sit well with him and did not contribute to a good dying process, as "he had to go on living like this, on the brink of disaster, without a single person to understand and pity him" (6).

While Ilyich's dying process was not good, his death itself was good because it culminated with an increased understanding between him, his family, and his fate. As Ilyich came closer to his death, he realized the way he treated his family, how he prioritized social standing and superficial relationships to true love and happiness. He realizes this through spending time with Gerasim

and his son. Approaching his death, Tolstoy writes:

The dying man was still screaming desperately and flailing his arms. One hand fell on the boy's head. The boy grasped it, pressed it to his lips, and began to cry. At that very moment Ivan Ilyich fell through and saw a light, and it would reveal to him that his life had not been what it should have but that he could still rectify the situation [...] Just then he felt someone kissing his hand. He opened his eyes and looked at his son. He grieved for him. His wife came in and went up to him. He looked at her. She gazes at him with an open mouth, and unwiped tears on her nose and cheeks, with a look of despair on her face. He grieved for her (6).

At this point, Ivan and his wife come to an unspoken realization about their failed past and how care and love is so much more important than material things. While this could have translated into regret and despair, the forgiveness from his wife and the lack of time he had on Earth brings Ilyich peace before dying. This realization helped him die a good death because he did not have to go with feelings of guilt of his past and bitterness of how he was also left alone during this time. Ilyich is able to die with those he does realize he cares about, a point that Dowling Singh stresses greatly:

May we assure our loved ones of our presence [...] May we let our loved ones know, when it is appropriate, that it is okay with us for them to stop fighting, it is okay to turn toward death and the profound passage awaiting them. May we let our loved ones know that they may die in their own absolutely unique way—not according to our expectations—and may we trust the process (15).

It is important for end-of-life patients to be with their loved ones, but it is also important for loved ones to get support and help in this time. Paul Kalanithi, neurosurgeon and writer, passed away from stage IV lung cancer in 2015, when he was in his late thirties. His dual role as a physician and surgeon sheds light on the dying process and the various elements involved. Kalanithi, in his memoir, eloquently expresses the effect of a patient's diagnosis on their family and loved ones:

For amid that unique suffering invoked by severe brain damage, the suffering often felt more by families than by patients, it is not merely the physicians who do not see the full significance. The families who gather around their beloved—their beloved whose sheared heads contained battered brains—do not usually recognize the full significance, either. They see the past, the accumulation of memories the freshly felt love, all represented by the body before them (14).

Therefore, it is hard for the family to realize that the person they love may not have the same capacities as they once did, before their diagnosis. While this is different and may take a while to process, with the help of certain professionals or other family members, even the patient themselves, loved ones will be able to reconcile this difference and come to acceptance.

Just as the patient can go through stages of grief when dealing with the end of their life, so can loved ones. As Kalanithi pointed out earlier, it is sometimes harder for loved ones when it comes to the suffering they feel after a close loved one is diagnosed terminally. Hannah Coulter, wife of Nathan Coulter in Wendell Berry's novel *Hannah Coulter*, illustrates this problem: she has a tough time dealing with her husband's terminal diagnosis and is not able to accept his death until long after he can. Hannah describes how she reacted after she found out her husband has incurable, terminal cancer: "I was beating the hell out of a dozen egg whites in a bowl. Why I had started making a cake, I do [not] know. It was what my hands had found to do, and I was doing it" (5). The raw emotion that Hannah is feeling is more than apparent in this passage. She knows that her "comfort for fifty years" will not remain for much longer once Nathan passes away. However, it seems as if Hannah is not able to directly face this reality even though she knows that it is irreversible. Instead, a mixture of emotions, which do not get sorted out until she has a meaningful conversation with Nathan about her thoughts and worries, clouds her thinking. In the meantime, her feelings of being "brokenhearted, furious, scared, and confused" are directed to her work in the kitchen instead (5). The passage shows that the best way for her to deal with this truth is to unknowingly divert her mind so that she keeps busy. It also seems as if she does this to channel her energy and negative emotions into a physical activity like whisking eggs. Though Hannah is

hurt with the prospect of life without her husband, she finally accepts what will happen to the both of them after she herself seeks help from Nathan. She learns to take Nathan's death maturely, and appreciates all he did for her, her family, and her community. Though she is pained at the thought of Nathan leaving her, she knows that his death would mean the end of his suffering and a beautiful culmination of a life so very well lived.

When loved ones learn how to take the dying process well, a good death can be better achieved. It is already difficult for patients to face death, but it gets harder when the family cannot let go. It makes it hard for the patient to think about non-earthly, spiritual, and meaningful things when they are so tied to involvements on Earth. One of Kübler-Ross's patients expresses his worry relating to his family and their dependence on him:

I will take this treatment and go home once more. I will return to work the next day and make a bit more money. My insurance will pay for my daughter's education anyways, but she still needs a father for a while. But you know and I know, I just cannot do it. Maybe they have to learn to face it. It would make dying so much easier (7).

He knows his responsibility towards his family, but at this point in his life, he wishes that his family would be okay and able to cope with what is happening to all of them so that he is able to pass away with more ease.

Satisfaction with Life and Alternative Perspectives of Death

Another factor that can contribute to dying a good death is whether the person was satisfied with the way they lived their life. This reflection on life can help patients understand that death is another stage of life and that their lives were well lived was a good and complete journey.

While Nathan Coulter in Wendell Berry's *Hannah Coulter* has this satisfaction, Ivan Ilyich does not. Nathan consoles his wife: "Dear Hannah, I'm going to live right on. Dying is none of my business. Dying will have to take care of itself" (5). As Nathan describes, his death is another part of his life. Instead of feeling down about his diagnosis, he uses his remaining time to do things that matter and make whatever is left count. He is satisfied with how he spent his life, which makes

it easier to accept his impending fate. He can go with the happiness of what once was. Dying a good death means culminating your life with meaning and appreciation of what you had and experienced in life. A person experiencing end-of-life care who is satisfied with their life can focus on important aspects that have positively impacted their lives. Being in certain places and remembering certain moments can help patients find comfort in their memories. Moments such as these may be bittersweet, but may help with finding an eerie ease and acceptance in what is to come (7).

By viewing death as an adversary instead of as a natural stage in life, Ivan Ilyich had more trouble grappling with death than Nathan. Ivan Ilyich thought he was leading a good life, one he enjoyed, but he realized on his deathbed that he had no satisfaction with life. With no one to call his own and no true and fulfilling friendship, love, occupation, and morality during the course of his life, he did not have the satisfaction that Nathan did. What did help Ilyich die a better death was coming to this realization and having support when realizing it. He realized the true meaning of life, but he also realized that he had wronged his family. Ilyich tries to ask them for forgiveness, but tells them to forget instead. At this point, he is not afraid of death. He realizes that he has learned what is right and that he has to leave his family in order to end both of their suffering.

Viktor Frankl's *The Unheard Cry for Meaning* provides us with an additional lens of why Nathan Coulter and Ivan Ilyich lead different lives and, consequently, view death differently. Frankl explains that "there is a healing force in meaning," when he explains the importance of "logotherapy" when dealing with dilemmas (16). Because Nathan Coulter led his life with a deeper purpose and meaning, and continued to reevaluate his life and his relationships throughout, he was more satisfied with life. Ivan Ilyich, on the other hand, did not have this search for meaning, which translated into an unsatisfied life. Though he may have thought that material goods satisfied him, he did not understand what that meant or felt like until the end of his life, as mentioned above. Frankl writes that "healing comes from the realm of the spirit," precisely the way Ivan spiritually heals to question his true meaning and importance in life (16).

Interestingly, Frankl creates an orthogonal axis: the x-axis spans failure to success, while the y-axis spans despair to fulfillment. Frankl explains that *Homo sapiens* operate on the x-axis: material goods, human achievement, and the like are all

indicators of a life well lived, and, consequently, an indicator of a good death. However, the y-axis, or the axis of the *Homo patiens*, measures fulfillment of one's self through meaning (16). When Ilyich switches his axis from x to y, he finds out that he lived life without true meaning. He thought that a good life would mean a successful one, not necessarily one with fulfillment. Coping with death is what shows him the stark reality of what was and what could still be.

Changing how we talk about death and integrating it into our lives can help us focus on the journey, decreasing resistance of death and dying. Elizabeth Kübler-Ross explains that it might help if people talk about death and dying in a more open fashion:

As an intrinsic part of life just as they do not hesitate to mention when someone is expecting a new baby. If this were done more often, we would not have to ask ourselves if we ought to bring this topic up with a patient, or if we should wait for the last admission since we are not infallible and can never be sure which is the last admission, it may just be another rationalization which allows us to avoid the issue (7).

She recounts that she has had many patients who were severely depressed and withdrawn until their healthcare professionals spoke with them about their illness and its terminal nature. After open conversation and a change in how you can approach death, Kübler-Ross said that their demeanors changed:

Their spirits were lightened, they began to eat again, and a few of them were discharged once more, much to the surprise of their families and the medical staff. I am convinced that we do more harm by avoiding the issue than by using time and timing to sit, listen, and share (7).

Spirituality & Religion

This existence of ours is as transient as autumn clouds.

*To watch the birth and death of beings is like
Looking at the movements of a dance.
A lifetime is like a flash of lightning in the sky,
Rushing by, like a torrent down a steep mountain.
-Buddha*

When facing the end of life, many find it

consoling to be a part of something greater than the self. Spirituality and religion can help a person cope with death and dying by giving them a deeper meaning and purpose, by uniting loved ones together, and by possibly considering life after death. Interacting and expressing these beliefs can help accept death and suffering as a part of life that has its own positives that come out of the experience (11).

Both spirituality and religion can help those experiencing end-of-life care by providing them with a deeper meaning of life and death, which helps them grapple more with the concept of death. Spirituality may or may not be linked to a specific religion. Therefore, those who are spiritual may not necessarily identify with a specific religion, and may just believe in the immaterial: the human spirit, soul, and the universe. Whether a person is spiritual or religious, the belief that there is something in our lives that is bigger than our physical selves helps many adopt a different perspective that can aid in their interaction with dying. This perspective may help those who are dealing with death and dying by providing the person with a more than worldly view. If a person knows that they can spend their life searching for a higher meaning or purpose, they can spend whatever time they have left doing something meaningful because they may want the rest of their life to count. It can also function as a time to reflect on the good and the bad, an ode to what once was and an appreciation and serene gratitude for it all. Instead of focusing on the material, those who focus on the immaterial can also know that there is still something that will exist even if the physical body does not, which may help cope with the death of the physical body. Dowling Singh cites Sogyal Rinpoche, a Tibetan Monk, to explain that our society does not nurture ourselves with the wholeness of spirituality. She writes:

We smother our secret fears of impermanence by surrounding ourselves with more and more goods, more and more things, more and more comforts, only to find ourselves their selves. All our time and energy is exhausted simply maintaining them. Our only aim in life soon becomes to keep everything as safe and secure as possible. When changes do happen, we find the quickest remedy, some slick and temporary solution and so our lives drift on, unless a serious illness or disaster shakes us out of our stupor (15).

This meaningful change, potentially in the form of a terminal diagnosis, can cause us to work on ourselves with the help of spirituality and learn by living and experiencing instead of running away or staying in our comfort zones.

Spirituality and religion can also help a patient cope with dying because of its ability to unite people together, which can help in this time of need. Robert Martensen mentions that he has noticed many terminally ill patients who went on spiritual and mystical quests, which helped them prepare for what was to come. Oftentimes, not counting the times a person needs to reflect inward on their own, it helps to have a group of tight friends, family, or contacts from a place of worship that function as a support system who can understand the person and help them work through their thoughts.

Religion and spirituality can also provide an assurance that a person's life does not end once it is physically over. Through concepts such as heaven, hell, and the eternal soul in both Western and Eastern conceptions of life, there is a life after death. Dowling Singh expands on this concept, first explaining that we are afraid of death because we are confined by our ego and its emotions such as fear:

Our fear of death arises with and coexists with the mental ego. Virtually all of humanity spends its adult life in a fragile and fragmented state of being, protecting and attempting to prolong the illusion of the separate, personal self. We live, lost at the surface, in fear, attachment, anxiety, and loneliness, motivated primarily by survival and control. Although fear can certainly be experienced before the development of a fully personal consciousness, the fear of death can only be experienced after that development. The fear of death is grounded in a strong sense of the 'I,' an attachment to a finite and separate self (15).

She then says that death is feared because it is seen as the end of our existence—an end that will send us into a void. However, this is “the only viewpoint available to the mental ego. Of course we are terrified of abandoning our separate sense of self when we know nothing else. And so, when we, as mental ego, hear the pronouncement of our terminality, there is no alternative but terror” (15). Dowling Singh believes that only parts of us can experience death, but not the whole. If we escape

from the confines of our mental ego, that surrounds us in fear and terror, then we will be able to see that death is not the end of our overall existence. This view can be consoling to those experiencing the dying process, and can aid in facilitating a death with less resistance from one's self.

Dowling Singh and Kübler-Ross have a mature understanding after working with patients who are terminally ill: "All patients have kept a door open to the possibility of continued existence, and not one of them has at all times maintained that there is no wish to live at all" (15). The will to live is one that carries on throughout the dying process until the stage of complete surrender is reached. The will to live not only provides depth and gravity to life, but it also intensifies the dying process (15). By keeping hope and faith alive, these patients may alleviate many stresses associated with dying. When Kübler-Ross reached the point of her own death, she said that even after all her work with terminally ill patients it was only "today [that she is] certain that there [is] life after death. And that death—our physical death—is simply the death of the cocoon. Consciousness and the soul continue on a different plain" (17).

Comfort in the Physical Death Itself

Knowing where a person wants to die can also be addressed before the actual moment of death and can help lead to a "good" death is, along with, whom they want with them, and any last wishes or requests they have. At the end of life, you remember the good and the bad, you think back on your life and note the moments that grounded you, but also helped you grow from those same roots. A good culmination of the physical death can be heavily reliant on these factors.

These factors may help a person who is dying feel comfortable mentally and physically by providing them with an opportunity where they can die with people who mean something to them, or in a place that is meaningful or comfortable for them. In a documentary about Kübler-Ross, she "kidnapped a lot of patients" because she wanted them to experience real joy instead of die in a hospital (17). Dowling Singh argues that if a person has clarity and has made peace with their death, then they may not be as picky with where they die as compared to with whom we are with and how we feel. I believe that all of this depends on how mature a terminally ill patient's relationship is with their dying process. It is something that needs to be thought about, but not only if death is near.

It is important to understand that these factors are not all necessary in dying a good death. Some take precedence over others depending on the individual's life and experiences. However, it is also very crucial to understand that there are other factors necessary to die a good death that are not mentioned in this section. These factors, such as stable socioeconomic status and access to resources, are not expanded on in this section because I operate on the assumption that the access to these things in should be basic necessities to an individual.

While this is not the case right now, delving into the complexities of such issues is not plausible for the scope of this thesis.

Part 2: Death of a Child and Pediatric End-of-Life Care

When a person thinks of death, they often think of someone of an older age, one who has been able to experience their life for a long amount of time. This is because death is thought of as a natural process at the end of life. Yet when death comes at a different stage of life, we think of it as unforeseen and abnormal. How can we prepare for the unexpected, such as the death of adolescents and the middle-aged? The most extreme form of this is the death of a child, which is hard to process for the child, the family, and the culture we live in. Since the death of a child is the most "unnatural" and unexpected, it would present with it many serious challenges to dying a good death. This section will explore whether a child can ever die a good death, especially if they were not able to live a long life.

The factors for dying a good death analyzed in the previous section all apply to some extent to pediatric end-of-life care as well. Therefore, the factors of pain and symptom management; patient dignity and autonomy; clear communication by healthcare professionals; stages of grief and eventual awareness and acceptance of death; emotional support and family presence; satisfaction with life; spirituality and religion; where to die; and any last wishes all apply to some extent. However, there are more factors to consider when looking at pediatric end-of-life care. The factors it takes for children to die a good death may be more complex, for both the patient and their loved ones, due to the complicating factors that come with dealing with an early death. After reading scientific literature and novels as well as talking to healthcare professionals, the main reason

the death of a child is so much more tragic is a combination of the loss of unfulfilled potential; the toll that the death has on loved ones; as well as with the complexities of development that come with age. Below is a chart that comes to a similar conclusion with the factors listed above (18). The two other factors I wish to bring in—helping the child understand their potential and caring for the family—are also shown in this chart, under “Legacy” and “Impact on Survivors.”

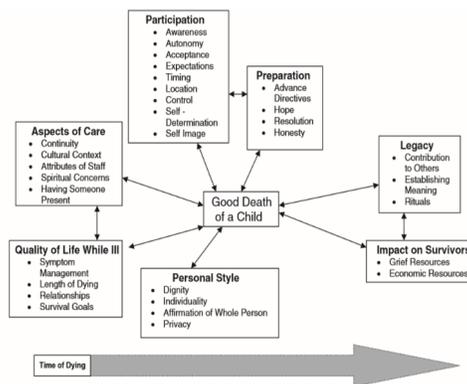


Figure 1. Proposed Diagram of the Relationship Among the Dimensions of Good Death of Child With Cancer as Viewed From the Perspectives of the Child, the Family, and the Health Care Provider

Figure 1. Flowchart of factors for pediatric end-of-life care.

A Complicating Factor

Before going into the two additional factors I argue play a role in facilitating a good death in the pediatric setting, I wish to briefly talk about the role of age plays in pediatric end-of-life care. As a child grows older, their conception of death and its associated feelings change based on what they know about their diagnosis as well as the topic of death and dying in general.

A younger child may not know what death is exactly, and may think of it as a word without any meaning and implications. Sahler et al. expand on the possible immaturity of a younger child, which is variable depending on their age and upbringing:

On the one hand, some children truly do not understand what death is, or are unable to comprehend future time beyond a few days. On the other hand, some children readily acknowledge impending death, want to be relieved of the burden of hoping for a cure, and wish for the opportunity to discuss their questions and concerns (19).

Therefore, there is an age-appropriate participation for a child’s death (18). When preparing for a child’s death, the different age and developmental levels will be involved in how a child can understand their terminal diagnosis. While a younger child may be unaware of death, an older child may have accepted their death and consider how they feel about their lives thus far.

As alluded to earlier, if a child is younger, not only might they not understand what death is, they can also have their family or loved ones hold back the truth about what is happening to them due to their lack of true understanding. It is important to note the complexity to withholding the truth from a child with a terminal illness, and omitting information such as the communication problems between the involved parties and the reluctance a physician may feel from not informing a helpless patient (18).

However, some scholars observe an admirable and not necessarily characteristic maturity in children. Because terminal illness and dealing with death both shape an individual, they may properly comprehend their impending death and see a larger purpose in life, even if they are merely children. Maturity may not be present in all aspects of behavior and personality, but it may be more developed due to the particular situation they have to face in regards to their death. Flannery O’Connor’s *Death of a Child* illustrates this. The book is a memoir about Mary Ann Long, a child with a cancerous facial tumor, who lived with a group of Dominican Sisters who took care of her during her last years of life. She was only 12 years old when she died, yet she touched the lives of many and lived a fulfilled life. Her relationship with good people on Earth and her later relationship with God and the afterlife helped her come to terms with her death. Mary Ann also embodied a child’s innocence, as she did not live long enough to have the same regrets and complexities as older people. Mary Ann did not have the regret that Ivan Ilyich did, so her life was purer. She did exemplify maturity and saw the good in people. She was worldly and non-judgmental. She let her whimsical personality impact the people around her:

Mary Ann would climb up on the patient’s bed and they would have long and serious conversations. In the next bed there was a patient who was noted for complaining about everything. [...] One morning the woman said her coffee was cold. Sister Josephine paid no attention, feeling that coffee had just come from the kitchen would certainly be hot. However, Mary Ann turned

around, took a spoon off her tray, jumped off the bed and [...] proceeded to put a spoon in the woman's cup of coffee. Everyone watched with interest as she tasted it. She put the spoon down, muttered, 'Stone cold,' and went back to her place on the bed (20).

This excerpt characterizes the child's wisdom and awareness of others. Of course, this may vary with age, but when a child is dying, they can surprise us with an understanding that is sometimes hidden in an adult.

A child's age and development plays a huge role in how they perceive their death. A child does not necessarily realize that they died a good death, especially if the child is younger and does not have a real concept of death. They do not necessarily know the implications of death, so it would be harder for them to ponder the overall effects of their life and death. However, there are certain aspects of their development that may be heightened and more mature compared to other children their age due to the particular obstacles they must face. It is important to keep in mind the differing views brought upon by age and development when examining the role of legacy and loved ones in dying a good death.

Legacy and Potential

Part 1.2 illustrates the potential factors for adults to die a good death. Leaving a legacy behind and by being spiritual were ways to live on after death. This concept is also applicable to pediatric deaths, but in a complex way. For children that die an early death, they may feel as if they were not able to live their life. Their loved ones may also feel guilty because child is not able to establish meaning and act on their unrealized potential. One way to combat this feeling is by understanding that life is not measured in years, but by quality and impact on one's self and others.

Helping others is good way to live on after death. In O'Connor's *Death of a Child*, while God helped Mary Ann come to terms with her death, helping other children had a positive impact on her as well. O'Connor recounts a time when Mary Ann positively influenced a woman and her terminally ill child:

Later, Stephanie's mother said, "By the time we brought the baby to the Home, I had accepted my child's affliction; I had accepted the hurt it brought me, but I had not accepted the fact I had to give her up. My husband was suffering, too, and my

attitude about bringing the baby was not helping much. Mary Ann's words opened my understanding. Stephanie was needed; she was [not] useless; this child with the bandaged face and a heart full of love needed her" (20).

Just as Mary Ann was able to live on through spreading goodness, B.J., a 9-year old with HIV/AIDS, wrote his own legacy through creative means: "I am a[n] acorn I am scared of sq[u]irrels and I am not scared of d[y]ing beca[use] I [will] grow back up again" (Weiner et al. 1994). By believing that he will still live on, B.J.--like many other children facing end-of-life care—are able to come to terms with leaving in a better way. People may struggle with the death of a child because the child is not able to live out years of their life, but what matters is the impact that they have on the people in their life and the love and memories they are able to evoke for the people who matter.

Weidner et al. believe that when encountering a child with existential pain and anguish in the end-of-life stage, it is important to answer their questions and comments as an opportunity to do better, not as a barrier that hinders their overall mental health. They recommend that healthcare professionals should speak directly to the child and craft their responses based on the child's age and understanding of their disease. When a child asks questions like, "Will you keep my pictures in the album?" it is because "children hope to gain reassurance that their lives have been meaningful and that they will be remembered," so that is what responses should be focused on (21). A good death for the child is often contingent on what other people tell them because they may not necessarily have the resources to self-reflect to such an extent, especially when they are younger. If healthcare professionals or loved ones make an effort to give children meaning in their lives and help them establish their own legacy, then it can help them die a better death.

The Role of Parents and Loved Ones

Regardless of the cause, the death of a child is hard to accept because it seems unnatural. As stated earlier, because children do not always have the same understanding of their terminal diagnosis; they may require help from their family and loved ones. Therefore, when you are younger, you may not know what death encompasses, so the involvement of the family may be larger. A

good death for a younger child involves peace and support from the family. It is also important for an older child, but they may also want to make sure that their family is okay once they are gone.

A significant difference between adult and pediatric end-of-life is the role of parents and loved ones in the death. Therefore, another factor one must consider for pediatric end-of-life care is the emotions of parents and loved ones involved. While I believe that a child can have a good death, it is important to understand how much of a role the child's loved ones have in this process. When faced with the death of a child, parents can struggle with various feelings. They might feel bad their child did not live to see and experience as much as they could have. They might also feel guilty that they outlived their child. They might feel guilt, thinking they could have prevented their child's death. Researchers also explain:

Parents are typically nurturers and mourn when their best efforts at nurturing fail. Parents despair at the loss of a beloved family member who is perceived as an extension of themselves. They are forced to deal with the loss of parental hopes of immortality through the life of their child. Anger may arise from their reality that their own precious child is one of the few to die. They question why not many others? Parents may be reluctant to discuss death with their child who typically suspects but can be confused by the parental response of denial or avoidance of impending death (22).

Parents must have resources and offer support. I argue this resource is a factor in facilitating a good death of a child. Because a parent or loved one means so much to the child, it is important to make sure that they are cared for during and after the end-of-life process. This measure can aid in alleviating any worry, fear, or anxiety about what will happen to the people they care about once they are gone.

A good way to conceptualize the importance of parental support is through Virgil's unforeseen death in Wendell Berry's *Hannah Coulter*. Virgil was young when he passed away as a soldier during World War II. Hannah, Virgil's parents, and the close community of Port William were highly impacted by his death. While Virgil was not a child, he was young. His death was unexpected, and his loved ones took on the burden of his death. Hannah explained that "sometimes [her] grief for Virgil

would become mingled with grief for [herself]. [She] didn't want to be selfish. In the midst of so much grief, [hers] and other people's, [she] feared the guilt of wanting anything for [herself]" (5). This is a common sentiment experienced with the death of a child. Parents and loved ones feel as if the pain they experience outweighs the pain their child experiences. Hannah and Virgil's parents looked for ways to change Virgil's outcome, as if there was something they could do (another common occurrence when dealing with the death of a child).

Parents and loved ones also have to make decisions for the children that can lead to feelings of guilt and pressure when the child passes away. When considering a good death for the child, it is important to make sure that the parents and loved ones feel comfortable doing so and are heard if they have any issues. von Lutzau et al. explain that pain can cause emotional distress for not only the person experiencing it but also for the person's family and loved ones. They expand that "the child's suffering would have an impact on the psychosocial functioning of the entire family. [...] Fatigue was a big problem in care and was not addressed much at all" (23). By making sure that the family is cared for during the dying process and not just once the death has occurred, we make sure that both the child and the family believe that the child has gone through a good death. In particular, researchers suggest:

Learning how to prepare a family for a potentially negative outcome while also maintaining hope is a skill that trainees will apply in many difficult situations, not only those involving terminal illness. This skill can be enhanced by regular discussions of the ethical issues involved in medical care and how to elicit a family's values during, for example, family meetings (19).

This gives parents and loved ones a say in their child's death and helps them feel as if they are active agents who can help better their child's death. By developing partnerships with families and supporting them in their caregiving efforts, we will be able to help the child's loved ones and help them understand that while their child is gone, they were cared for and died in a good way. Once the child has died, grief counseling and other resources can be offered to the child's loved ones to ensure that they are being cared for or are doing well after the traumatic event.

Along with caring for the child's loved ones, I also believe that having them present and involved in their child's death is crucial in dying a good death. Because a child is unfamiliar with death and is uncertain of the future, having loved ones surround them can help. When Mary Ann was away from her family, she wished for the things she loved to be close to her so that she could die happily: "Mary Ann had all of a child's longing for the home with her mother and father and sisters which her imagination pictured. She had always liked to pretend that the yard behind the home was populated with her connections" (21). As Mary Ann illustrates, a flourishing environment with people the child loves and wants to be around can be good for them at the end-of-life stage.

Terminal care can be provided through home care, which can aid in surrounding the child with people they love, in an environment they are comfortable. Healthcare professionals can recommend that home care might be fruitful for some families and children who wish to be in familiar surroundings, with people that bring comfort. Nurse and researcher Elizabeth Whittam explains that through home care:

The child's isolation from the family is diminished, participation in family routines and selected outside activities become possible, care of the child can be shared among extended family members and friends, and siblings are afforded more opportunities for communication and participation. Most important, parents know their children. When assisted, they can provide far better, more individualized care than many professionals. In addition, being able to fulfill the child's wish to remain at home is a source of pride and accomplishment for the entire family (24).

Of course this is not the preference of every child dealing with death, but it is an option for children who want to be around the people they care about during their last stage of life.

Mary Ann beautifully illustrates the complexities of the death of a child. Mary Ann's terminal diagnosis may have given herself, her family, and the Sisters time to process things, but this did not make the feat any easier over time. Therefore, the death of a child is not something that you can cope with in a linear fashion. It involves good and bad moments, hardships, and growth over time. Consequently, the death of a

child is not something that is easy to accept. It is a hard concept to grasp because of guilt and fear. Age plays a significant role because the development of a child impacts how they perceive death and handle their end-of-life care and decisions. Mary Ann was nine years old, but was very mature for her age. She was said to have a very worldly perspective and used to take the blame for things other people did without any attempt to justify herself or clarify the situation (20). Because Mary Ann was so understanding, she took the role of spreading love and positivity to others, even though she was the one dying. Mary Ann had a legacy that lived on after her death. The Sisters were positively impacted by the child's wisdom and astuteness, as well as her selflessness. Whether it was giving people a second chance or bringing warmth and smiles into people's lives, Mary Ann left a positive impression on the people in her life and set an example for them. This would live on long after she died. Age also impacts how much of a role family has in the child's death and how the family and loved ones can be impacted. The Sisters who took care of Mary Ann were sad about her passing, especially because she was so young. However, their hearts were filled with goodness because they knew that Mary Ann served God and lived a life full of love and sincerity. Mary Ann's loved ones also played a critical role in her wellbeing and contributed to her peace of mind, which helped her live a good life on Earth. Therefore, by involving the child's family and loved ones in their death if the child wants will aid in the child dying a good death because children want to be around those who love them and bring the good out of them.

A child's death can be heartbreaking. Some may ask how a child's death can ever be anything other than devastating. After all, a child was deprived of happiness that they could have experienced throughout their lifetime. While a child's death can never be easy to process, understanding all the intricacies that come with the end-of-life stage and the lessons that can be taken away are ways to deal with the hardship.

Part 3: Insight from Healthcare Professionals: On Death and Dying

After analyzing the factors it takes for adults and children to die a "good death," I believe that it is beneficial to understand the potential feelings and aspects that various healthcare professionals grapple with on a day-to-day basis when addressing death. In order to better understand this, I

conversed with healthcare professionals such as researchers, social workers, clinical psychologists, clinical ethicists, and physicians about their experiences and practices when interacting with both children and adults in the end-of-life stage.

Healthcare professionals are individuals who often dedicate their lives to serve others, and understanding their experiences and feelings will add a dimension not captured by books or journal articles. By talking to individuals who have committed to being good, moral, and virtuous healthcare professionals, we will be able to receive guidance from their experiences, a concept Aristotle calls *phronesis*, or practical wisdom. Physicians and other healthcare professionals can learn what to do, but it is important for them to use their own thinking and judgment when making complicated decisions. These are actions that transcend following the rules (25). Therefore, it may be easy to establish rules and know what is right, but it is harder to actually practice these things socially and in a virtuous way. For example, a doctor needs to treat a patient well and be honest with them about their terminal diagnosis, but they also have to be considerate of the patient's past experiences, various identities that can impact how the patient may perceive this illness, and that the patient's preferences may or may not match up with the doctor's first choice treatment plan. This cannot be done well if a "one size fits all" rule is followed. Virtues and practical wisdom need to be incorporated in the doctor's actions. The following conversations with healthcare professionals illustrate the importance of practical wisdom when dealing with death and dying.

In this section, I will attempt to shed light on some of the emerging themes and feelings that were talked about during our conversations, as well as potential ways to make the dying process more humane and considerate. The topics explored include the unique nature of the dying process for every family; the importance of being considerate; the importance of communicating well and with each other; preserving a child's relationship with their loved ones; knowing the patient's preferences creatively; the possibility of life after death; how healthcare professionals cope with their patient's death; and the role of technology in end-of-life care. While this is not a formally conducted interview analysis, the interviews illuminate important themes in regards to death and dying. I have also incorporated scientific journal articles and Paul Kalanithi's *When Breath Becomes Air* to supplement this analysis.

Dealing with Family's Wishes is a Unique and Individual Process

"Every family is unique, and every death is unique."

-Dr. Cynthia Gerhardt, Nationwide Children's Hospital

In an attempt to understand how healthcare inequities and identity differences play a role in dying a good death, I asked healthcare professionals how to approach families of different races, classes, genders, etc. Is this something that is formally taught to them, or is it something that they had to learn along the way? Specifically, I was interested in how they incorporate identity difference in their approaches to end-of-life care.

All healthcare professionals recognized that identity differences are certainly important to acknowledge, but the main focus is to understand that these identity differences should not be generalized and assumed. Therefore, each situation, each family, and each patient is unique in their own way. While customs and religion may play a role in some of their lives, this should be learned on a case-by-case basis instead of on one overarching generality. Dr. Cynthia Gerhardt, director of the Center for Biobehavioral Health and co-director for the Patient-Centered Pediatric Research Fellowship at The Research Institute at Nationwide Children's Hospital in Ohio, emphasizes patient's uniqueness among healthcare professionals with a "families as faculty" process: "It is important to understand expectations and core beliefs and be an observer of the process" (26). In essence, it is important to learn from the families in order to provide efficient care. Dr. Elissa Miller, a physician in the Palliative Care Department at Nemours duPont Hospital for Children, expands on this exact sentiment:

It certainly was taught to me, and it should be the focus of all palliative medicine fellowship programs. The way it was taught to me was that you do [not] ever make any assumptions about anybody, and you just always ask. Every person is different, and every family is different. [...] Aiming for uniformity in practice [is another important factor in all of this]. If I reach out to hug one family, I reach out to hug another family. I really

try to make sure that I am addressing my implicit biases, we talk about this all the time with our team, and making sure that we are treating our families equally (27).

Dr. Miller utilizes practical wisdom to understand that while it is important to be uniform in how you treat each family, it is equally as important to realize that each family comes with unique experiences and beliefs, which healthcare professionals should take heed of.

Being Considerate

“It is important to be accurate, but you must always leave some room for hope.”

-Dr. Paul Kalanithi, Stanford University School of Medicine

When speaking to healthcare professionals, they all stressed the importance of being considerate to the patient and treating the patient and their family as human beings deserving of respect. Once Kalanithi was diagnosed with stage IV lung cancer, he experienced both sides of the healthcare system, as the doctor and the patient. He treated his patients in such a way that he was able to respect the patient for who they were, not just viewing them as their diagnosis. With one patient, he decided that he needed to break the news in a considerate manner:

Based on the scan, there was no doubt in my mind that this was a glioblastoma—an aggressive brain cancer, the worst kind. Yet I proceeded softly, taking my cues from Mrs. Lee and her husband. Having introduced the possibility of brain cancer, I doubted they would recall much else. A tureen of tragedy was best allotted by the spoonful. Only a few patients demanded the whole at once; most needed time to digest (14).

By being considerate of the patient and her husband, he decided to share her diagnosis in a way that would allow for them to process everything slowly and maturely. Kalanithi brings up a point about survivorship, where he says that it is important to be accurate with how long a patient may have to live. This cannot be done in an insensitive way. He says:

Rather than saying, “Median survival is eleven months” or “You have a ninety-five percent chance of being dead in two

years,” I’d say, “Most patients live many months to a couple of years.” This was, to me, an honest description. [...] I came to believe that it is irresponsible to be more precise than you can be accurate. Those apocryphal doctors who gave specific numbers (“The doctor told me I had six months to live”) [...] Who were they, I wondered, and who taught them statistics? (14).

Therefore, in the fear of being “statistically accurate,” we can compromise our integrity and humanity, and leave the patient in a worse state. It is important to be thoughtful when notifying the patient about their diagnosis and prognosis, especially in such a vulnerable time of their life.

The Importance of Communicating Well and Working Together

“If you think that there is nothing that you can do to help, then you have to tell them that, or else they will be thinking that you think it is the right thing to do, too.”

-Dr. Elissa Miller, Nemours du Pont Hospital for Children

Healthcare professionals strongly emphasized the importance of clear communication, especially with patients with a terminal diagnosis or receiving end-of-life care. Some professionals believe that communicating with both young and old patients about how much time they have left to live is challenging. There can be reluctance on the part of professionals to communicate and that can cause discomfort. However, it is really important to make sure that the patient and their family members have a common understanding and know all possible trajectories. This is a good way to approach death and dying, for there is open communication and a strong support system comprised of both healthcare professionals and loved ones.

First, it is the job of healthcare professions to make sure that the family understands the possible trajectories that come with a certain diagnosis:

It [is] a process of trying to understand, what do each of them know, what are they told, what do they believe. [...] Fleshing out the discrepancies between what communication has been relayed to them and what have they done with that communication, what are they putting their

faith in and believing in, and what are they disregarding from that. Even within families, they may have different discussions or perceptions of how much a child should be told that is appropriate (26).

It is then important to be upfront with the family with the possibilities, thereby incorporating the possibility of death and dying in a mature way. Wendy Pelletier, a social worker at Alberta Children's Hospital in Canada expands on this:

When a child is newly diagnosed with cancer, part of our work with the team, should be to talk about palliative care concepts pretty up front. So, we talk about the child's diagnosis, the trajectory of the treatment, over the 2-3 years, or 6 months, or whatever their treatment plan is, we talk about what is important to the family, what they want for the child, trying to talk about how things can go either way, throughout, their hopes at the beginning, of course, for a cure, but that there are certain things that can happen along the way, and just bringing that potential up front. [...] we are involved as a team (28).

By working together as one unit, healthcare professionals and their families can address issues directly. Another important aspect of communicating well is making sure that you give patients and their loved ones your honest opinion, and keep the interest of your patient at the forefront of your medical decisions. Dr. Miller explains the importance of being clear with the patients:

You never want to lie to a family, and you want to make sure they know what treatments are available, but it is acceptable to stress what your recommendation is. If you think that there is nothing that you can do to help, then you have to tell them that, or else they will be thinking that you think it is the right thing to do too. The family can be actively involved and can make the ultimate decision as long as they have heard all the options in an honest way, and how that will affect the child (27).

When working with the pediatric population, it is vital to let children guide the discussions and ask questions. Pelletier says it is important if we are "opening the door for younger kids to ask questions,

rather than laying a bunch of information on them. I think with adolescents it is a bit different" (28). If there is a breakdown in communication however, clinical ethicists and other healthcare professionals are there to restore this dynamic:

Many families feel as if they add more treatment, it will help the patient and give them more hope. The clinical ethicist helps the family understand the bigger picture, and tries to explain that we need to make this peaceful for both the patient and family (29).

If there is no communication established between all parties involved, it would negatively impact the experience of the patient involved. It is important that the patient's state of mind and wellbeing is kept in mind when their future is uncertain, and a great way to do this is to make them feel as if they are an active part of their dying process.

Working as a Team

"If I am not able to do that, then I am going to trust my team."

-Dr. Pamela S. Hinds, Children's National

Not only is it important to communicate well with the family and the patient, but it is equally as important to communicate with the other people that are a part of the healthcare team. While the roles of healthcare professionals overlap at times, each professional usually does not have the same level of closeness or understanding about the background or personality of the patient in question. Therefore, it is important for each member to work together and fill in the holes so that the patient gets the best care. Dr. Pamela S. Hinds, director of the Department of Nursing Research and Quality Outcomes at Children's National, gives an example of the roles that healthcare professionals perform:

"So if you are the nurse who is assigned to that child, day after day, hour after hour, I think you know amazing things about that child. And you know nuances. You know if their color changes, you know if the sound of their voice changes. [...] You are at that point of care with that child, moment to moment. If I am a doctor, I can[no]t know that because I can[no]t be in the room that length of time. But if I am a doctor then I am going to listen really well, I am going to try to ask wise questions. [...] If I am not

able to do that, then I am going to trust my team. And hope that they are able to hear, listen, be present, etc.” (30).

When dealing with death and dying, trust and good communication is especially important to keep in mind throughout the patient’s time in the hospital. Because the patient is vulnerable, both emotionally and physically at this time, it is the healthcare professionals’ job to understand the patient and be there for them through every change or question they may have. Without team support and collaboration, this would be very challenging to do, given the high demands of the profession and the fact that not every healthcare professional will be with one patient all the time.

Preservation of A Child’s Relationship with Themselves and with Their Loved Ones

“The last thing that you want is for a child to die an emotional life away from their parent, and for a parent to be isolated and to have regret after.”

-Dr. Lori Wiener, National Cancer Institute

During the dying process in a pediatric setting, it is important to make sure that a child can wrestle with aspects of dying in a matter conducive to learning and understanding in an age-appropriate way. It is equally important that a child and their loved ones are able to cope with death together as well. Firstly, if the child does know about their terminal diagnosis, it is the duty of healthcare professionals to make sure that the child has a platform to understand what comes with this diagnosis. Dr. Lori Wiener, co-director of the Behavioral Health Core at the National Cancer Institute, says:

[Healthcare professionals should] want to have an opportunity for the child to be able to share their concerns, their worries, their fears, their hopes, their dreams, and what they would want their tomorrow to be. So I do a lot of writing with kids as well, so they can be able to say things that they want people to know, and how they want to be remembered, and just to be able to say thank you. Gratitude is incredibly important, and forgiveness is incredibly important (31).

By working with children through recreational activities such as art, reading, and writing, she tries to make sure that children are able to ask

the questions on their mind about their own life and death. Healthcare professionals noted time and time again that children worry about leaving behind their family. Because family and loved ones play such an important role in a child’s life, the feelings that come with potentially losing them are important to address as well:

It [is] all about being separated from their loved ones and it could be worry of not seeing them or not being together. It really changes. [...] But not having the opportunity to communicate, what it is they are going through, what it is that they are feeling, what it is that they are experiencing, to be able to know that their parents are going to be okay, to be able to know that they have done everything possible, [...] to know that they are not alone and never be alone. [...] I think those are important criteria for having a “good death” or a good separation, or a good way to be able to transition, for their body to be able to let go (31).

Therefore, to aid in dying a “good death,” it is worthwhile to reconcile the feelings of the child, especially with regard to their family.

Creative Ways to Know Patient Preferences

“Truthfully, I can’t tell you how many families, [when their child became seriously ill], would say to me ‘I do [not] even know what my child would want,’ and I was able to say, ‘I do,’ and that [is] a problem because it should [not] be me that knows that, it really needed to be them that knows that.”

-Dr. Lori Wiener, National Cancer Institute

Especially when dealing with the pediatric population, it is important to know their wishes when it comes to death and dying, but a young patient requires different methods than adults, because not all children have the same rational faculties. Dr. Wiener developed a method that includes psychosocial assistance. Wiener researches bibliotherapy, artwork, and writing. These methods help healthcare professionals understand what the patient feels and experiences without a direct conversations. Wiener truly understood the child’s thought process and feelings on death and dying through this practice:

Every time they came, we did another kind of writing [...] sometimes it was the

alphabet [...] I also created a therapeutic board game called ShopTalk, there [are] three versions of it, there [is] a version for children, a version for brothers and sisters, and a version for children whose parents are sick [...] you learn a tremendous amount. So it could be sing a song, your favorite song, to if you are going to die from your disease, who is going to be the hardest person to say good bye to, how do you want to be remembered, things like that. [...] so, between the poetry, [...] the creative writing, and their artwork they did, it really helped them think about the fact that their life may be shortened, what would make most meaning for their life right now, what they would like to be able to communicate with family and friends, and how they would want to be remembered (31).

Wiener also used workbooks to understand pediatric patient end-of-life preferences. Dr. Wiener created This is My World:

I had kids help me design each of those pages of that work book and one day, a particularly precocious 11 year old said I think we should have my mock will and I said, "Really, tell me about that," and she put her hands on her hips and she said, "You adults think that you [are] the only ones who think about who would want their stuff?" (31).

Dr. Wiener realized that a dying child also struggles with questions that adults do. In her mind, it was imperative for them to be able to express these thoughts. She continues: "I started doing work in 2007, on the process of creating an advanced care planning guide [...], creating *Voicing My Choices*, [...] it [is] the only advanced care planning guide for adolescents and young adults" (31). *Voicing My Choices* allows for adolescents and young adults to make decisions, ranging from how they personally want to be comforted, to legal decisions, such as who they would want as their healthcare agent and what treatments they would be okay with undergoing. This is very important because children especially do not have a chance to partake in their medical care, and it is crucial to know what the children really want in a way that is not too overwhelming.

Larger Impact and Possibility of Life After Death

"Some people do [believe in an afterlife] and some people do [not], whatever their spiritual beliefs may be, it [is] still that they are going to live on in some way."

-Dr. Lori Wiener, National Cancer Institute

Patients—both adult and children—often come to terms with their death when they are given a larger perspective of death. When they are told that passing is not the end or that they will live on in other ways, it is sometimes more feasible for them to grapple with the possibility of dying. Dr. Wiener expands on this process of providing emotional comfort through these means. By caring for, supporting, and acknowledging their thoughts and decisions, we can aid in bringing peace and comfort to the dying individual. She believes that it is important to know how they want to be remembered after they are gone and concerns they have for those who are going to survive. She says that those who are not able to say goodbye or feel like they made a difference in their lives are the ones who have a lot of distress at the end of life, which shows how important it really is to bring things into perspective. Dr. Wiener shares that a good death is not just physical for reasons such as the ones stated above:

If you think about a good death, I do [not] just think about dyspnea, I do [not] just think about the physical pain, although that [is] clearly important. I really think about the emotional comfort and peace that they are able to experience and ways to be able to experience that is to be able to believe that their life made, that their life was meaningful, that their life made a difference, that their family and friends, people, will be okay, and they can give something to give them some peace, that they will never be forgotten, and that people will really be able to learn from their experience. And those who also have faith that one day they may be together again or some kind of sense of peace. [...] Some people do and some people [do not], whatever their spiritual beliefs may be, it [is] still that they are going to live on in some way (31).

Healthcare professionals stressed that

spirituality and religion often help patients come to terms with death and dying. While not all patients may believe in God and/or the afterlife, those that do tend to find comfort that this is not the end. The belief in the afterlife helps ill children, for example, to share a belief that they would be reunited on the other side and would have angels guiding them in this process (Ferrell et al., 2016) (Pelletier). What these sentiments have in common are the fact that the individual will still live on in some way, whether it is life after death or in the hearts of those here on Earth.

How Healthcare Professionals Cope After Death of a Patient

“It [is] those families that we did [not] reach or were [not] able to help that haunt me. You know the story, you remember the things you have done wrong a million times more powerfully, than the things that you may have done right. For the most part, knowing that I made a difference can really help people get to the place where they can be, as sad as it is, as unfortunate as it is, as unfair as it is.”

-Dr. Lori Wiener, National Cancer Institute

Healthcare professionals stressed the importance of seeking psychological help when faced with a patient’s suffering or death. Adjusting to the patient’s death can take a toll on the individual, but there are certain healthy ways to cope with the dying process. Healthcare professionals stated mindfulness and self-care as very crucial aspects of life that should be built into their days. A popular example was communicating with the healthcare team involved in the late patient’s treatment. Losing a patient is difficult for healthcare professionals, and sometimes it is easier to rely on those who go through the dying process with you instead of on a family member or spouse. Dr. Pamela Hinds recounts:

Some of your best people are the [ones] around you at work who have also gone through what, because they too know what it was like to go home and not have someone to talk to because [...] it is too hard to hear about dying children (32).

Dr. Rebecca Pentz, associate professor at Emory University and former clinical ethicist at The University of Texas M.D. Anderson Cancer Center, echoes the need to debrief with her team after a death occurs. Wendy Pelletier, a social

worker at Alberta Children’s Hospital, explains that it is helpful to understand death and dying while it is happening instead of when it has happened. Because death and dying have many implications and facets, it is better to expose yourself to the many feelings and emotions that it can lead to beforehand. She says that the healthcare professionals prepare with the family ahead of time, and that it is also a preparation for themselves in a way. The physical death may not be as hard as the whole process, and that is why it is important to wrestle with all the questions and emotions throughout.

Another way that helps healthcare professionals and families cope with the patient’s passing is making sure that they have helped families during this time. Focusing on the positive outcomes that the experience brings enlightens a new perspective for both healthcare professionals and the families. While this may seem difficult—or even inhumane at times—it is important to find solace after grief. Dr. Gerhardt expresses:

Many parents and children go to the process of legacy-making and meaning-making to deal with their grief, and so on the back end of it, they find some way to integrate the purpose and the meaning of that child’s life to help them kind of focus on the positives and the gifts that that child brought to them, and not just the loss (26).

She also illuminates a very important issue: the rigid time frame of grief and how it is unfair to define it with such stringent guidelines: “We have the [*Diagnostic and Statistical Manual of Mental Disorders*] (DSM) criteria for mental disorders, and, [...] you have to be over your grief in essentially 6 months, or they pathologize it, which I think does a disservice to families, you know, to overly pathologize them” (26). There should not be a time limit to healing. It is the job of a healthcare professional to make sure that the family has enough time and resources available to them, whether they choose to take it or not.

Many healthcare professionals said that staying in touch with the families is important, but it is okay if families want to be hands-off due to past grief and traumatic stress. Healthcare professionals send cards or letters, on the anniversary of the child’s death or the child’s birthday. A study on pediatric oncologists also showed similar follow-up practices with families, such as contacting them with a condolence card or an email; making a phone call;

attending funerals; attending visitations; having short-term and long-term meetings with parents; and attending memorials (33).

Mindfulness, self-care, being there for each other and for the late patient's family are all ways to cope with the death of a patient. They can help healthcare professionals cope with a patient's death by reminding them that the end of a physical life does not mean the end of the effect that the patient's life had on the people involved. Again, these practices are not required, but they do aid in helping the healthcare professional understand the process of death.

The Role of Technology in End-of-Life Care

*"I think technology can be both friend and foe."
-Dr. Pamela S. Hinds, Children's National*

Many healthcare professionals reinforced the dual nature of technology. Though technology can have both positive and negative effects, the healthcare professionals stressed that we must adjust to technology and make sure that we are honoring our preferences every step of the way. For example, just because a life-sustaining technology is available, it does not mean that the patient has to utilize that technology during their end-of-life care. Dr. Pentz, who worked as a clinical ethicist, shared that the role of technology and life-sustaining treatments came up a lot during her work at the bedside. It is important to know when it is appropriate to use it, and that the use of technology does not necessarily imply a better death. Therefore, technology should not solely be meant to prolong your life, and should be utilized to enhance it in some way. And if it cannot do that, if it can only prolong it without taking away the pain and suffering, then it might be wise to reconsider the decision of utilizing it.

Two interesting implications that technology brings about were brought up in my conversations with the healthcare professionals: social media and telehealth. First, Dr. Wiener stressed that technology and social media play huge roles in death and dying currently. Not only can they make coming to peace with your death harder because of the constant comparison between the lives of those who post on social media, but it can also bring about the rise of "pseudo-friends," who pretend to commiserate with the dying patient's struggle, but do so for more self-centered and self-motivated reasons. While not everyone reaching out to a person in end-of-life care is disingenuous, there

are people who may do so in order to look better in other people's eyes, promoting a positive image of themselves on social media. Some "pseudo-friends" might even pretend to care for a patient with a terminal or critical condition for pity or attention once the patient passes away. For example, if a person talked to the patient who passed away, they may get more attention from others while they mourn the loss of a friend. Secondly, Dr. Miller talks about her work with using technology to bridge gaps and inequalities in healthcare through telehealth and telemedicine. To reach remote areas and relieve healthcare disparities in the access of certain types of medical care, Dr. Miller and other palliative care physicians utilize telehealth and telemedicine through video conferencing services. Her studies on this matter also show that technology can be used for the good, as patient and family counseling in the realm of palliative care and bereavement support report its efficiency (34,35).

Conclusion

*Echo of the clocktower, footstep
in the alleyway, sweep
of the wind sifting the leaves.*

*Jeweller of the spiderweb, connoisseur
of autumn's opulence, blade of lightning
harvesting the sky.*

*Keeper of the small gate, choreographer
of entrances and exits, midnight
whisper traveling the wires.*

*Seducer, healer, deity or thief,
I will see you soon enough—
in the shadow of the rainfall,*

*in the brief violet darkening a sunset—
but until then I pray watch over him
as a mountain guards its covert ore*

and the harsh falcon its flightless young. (36)

The poem *Prayer* by Dana Gioia comes to mind when I think of my closing remarks. *Prayer* is a plea of a father who has lost his son. The father calls to God, the being present in every silence, the creator of the intricate details in nature, and the guardian of the Earth and afterlife, to protect and love his child. The father knows that he will see Him soon enough, but until then, he has only one prayer: for God to watch over his child: "as a mountain

guards its covert ore/ and the harsh falcon its flightless young” (36). The father surrenders his child to God, for He is present in all things and is the one who gave us this life. Because the father’s role is to protect his son through everything, the father relies on God, his supreme father, for He can keep us and our loved ones safe and loved, He can alleviate our fears, and He can take away all our worries in bliss.

Gioia’s poem carries many themes I present in my thesis. The poem shows the role of family and loved ones in a person’s death, the heartbreak and difficulty when dealing with the death of a child, the use of creativity in understanding the dying process, and the importance of spirituality and religion that some people look to in order to cope with death and dying.

All in all, in this thesis, I analyzed the role of death and dying in our society. I explored what it means to die a good death in the past and in the present; critically interrogated the possibility of both adults and children dying a good death; the factors it takes to die a good death; and the role healthcare professionals play in end-of-life care. I utilized novels, scientific journal articles, and firsthand accounts to do so.

I first traced the meaning of dying a good death throughout various time periods. In prehistoric times, death was an experience with no prior consciousness, since it often happened suddenly and had no room for reflection and search for meaning. Death, however, changed in perception when it became more predictable, which caused human beings to be able to think about death and study it. Both Eastern and Western philosophy contributed to the understanding of a good death, especially emphasizing the role of a life well lived. An amalgamation of historical pre-modern, modern, and post-modern thought defines the perception of death and dying in modernity. While how you lived your life definitely plays a role in how good of a death you can die, due to the development of healthcare and technology, the meaning of death can be less personal and more technological. Death can be considered something that was avoidable and ultimately a failure of medicine. However, it is important to understand that death and dying is a natural process of life. Prolonging death is not necessarily a good one. Death should be regarded as a time to reflect on, understand, and accept things, all while caring for the other physical and mental aspects of dying.

In the first part of my thesis, I analyzed novels and scientific journal articles to understand what

it means to die a good death. Through analysis from Wendell Berry’s *Hannah Coulter* and Leo Tolstoy’s *The Death of Ivan Ilyich*, we were able to understand this phenomenon. While Nathan Coulter understood that death was a way to culminate life with meaning and appreciation of what you experienced and cherished throughout it, Ivan Ilyich led a life without contemplation and truth, and denied his death and suffered until just moments before it. Though Nathan Coulter and Ivan Ilyich led different lives, I do believe that they ultimately die good deaths. With help from these two fictional characters, I completed a comprehensive analysis of the factors that play a role in dying a good death, including pain and symptom management; patient dignity and autonomy; clear communication by healthcare professionals; stages of grief and eventual acceptance of death; emotional support and family presence; satisfaction with life; spirituality and religion; where to die; and last wishes.

In the second part of my thesis, I looked at the phenomenon of dying an early death in its most painful and unnatural form: the death of a child. I argued the factors it takes to die a good death for adults translates to pediatric end-of-life care. However, two additional factors—the role of the family and legacy making—play a huge role in coming to terms with dying a good death. These two factors cannot be fully applied without understanding the role of age and development, which severely impacts how a child perceives death and applies it at the end of their life.

In the final part of my thesis, I incorporated conversations with various healthcare professionals, and inquire about their experiences and practices when interacting with children and adults in the end-of-life stage. After speaking with them, I extracted themes that were brought up during our conversations. These themes included the unique nature of the dying process for every family; the importance of being considerate; the importance of communicating well and with each other; preserving a child’s relationship with their loved ones; knowing the patient’s preferences creatively; the possibility of life after death; how healthcare professionals cope with their patient’s death; and the role of technology in end-of-life care.

The Falvey Scholar Award

The Falvey Scholar award is an annual program of the Falvey Memorial Library to recognize outstanding undergraduate research. It is a collaborative initiative of the Library and the Center for Research and Fellowships. The winners of the Falvey Scholar award are selected from a pool of candidates that will be generated by applications submitted by a senior Villanova University student or a group of students working on a senior project together with the recommendation of the advisor to the senior thesis or capstone project completed for academic credit.

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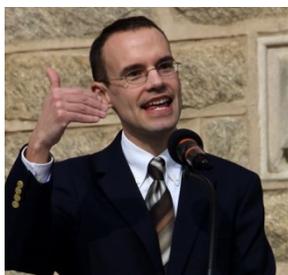
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Mentor

Dr. Angela DiBenedetto

Angela DiBenedetto is a faculty member in the Department of Biology at Villanova University. She received a B.S. degree in Biology with a minor in Latin and Greek from State University of New York, Binghamton, and a Ph.D. in Genetics and Development from Cornell University. Dr. DiBenedetto's laboratory research is conducted with student collaborators and aims to understand the role of genes in the process of animal development, using the zebrafish embryo as model teacher. She has taught many different biology courses, including Recombinant DNA Technology, Genetics, Experimental Genetics and Epigenetics, and, together with a colleague in the humanities, team-teaches a special interdisciplinary section of ACS, the core humanities course for first year undergraduates.



Mentor

Dr. Michael Tomko

Dr. Michael Tomko is associate professor and chair of the interdisciplinary department of Humanities, where he studies literature in light of religious, ethical, and cultural questions. He is the author of *British Romanticism and the Catholic Question* (2011) and the award-winning *Beyond the Willing Suspension of Disbelief: Poetic Faith from Coleridge to Tolkien* (2016) and also served as co-editor of *Firmly I Believe and Truly: The Spiritual Tradition of Catholic England* (2011). He has been recognized at Villanova for both his teaching and research as recipient of the Tolle Lege Teaching Award for Excellence in 2016 and of the inaugural University Mid-Career Scholar Award in 2018.