Creating Meaning Through Storytelling at the End of Life

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Hypothesis and Introduction

Since fifth grade, I’ve been telling and retelling the same stories.

One starts on a fall day in Baltimore when I was in third grade. I had made plans to walk around the block and visit my grandmother in her backyard garden. We were going to paint our toenails and sip lemonade to get her “ready” for her surgery the next day. Instead, I decided to stay home and watch cartoons after finishing my homework. When I went to walk the dog that night, I kept my head down and picked up the pace of my step as I passed her corner. The next day, walking down the school parking lot for carpool, I couldn’t find my Mom’s gold minivan, and our neighbor took us home. When my siblings and I finally got home, we learned there had been complications in my grandmother’s surgery that day and she died. My aunts and uncles--her children--had decided to “pull the plug” that afternoon. When they arrived at the hospital, they told us, she was already dead because her brain was no longer working. They told us the story of her last moments and how they held hands as her life support was removed.

Another story starts with my grandfather, the George Bailey of his small Maryland town, when towns were still small enough to have characters who made that large of an impact. Most of my memories of him, however, are from the days when he walked around the house with an oxygen tank in tow. The day that he went to have his pacemaker battery replaced, he entered the doctor’s office in his bathrobe and slippers, no longer the grand
man he once was. His doctor suggested maybe it would be best for him to simply go home
that morning, and he did. A few weeks later, after an afternoon spent in the backyard with
his children and grandchildren, swapping stories and laughs, he passed away in his sleep,
in his own bed, with his wife sleeping next to him.

The last story starts with that wife, my other grandmother, the day she died, and her
children gathered around her bed in that same house. The quiet room was filled with the
whispers of my parents, aunts, and uncles praying the words she had requested that they
pray as she breathed her last. Later that afternoon, as her grandchildren ran around the
backyard and played, her children sat in the warm July sunshine talking about their
mother, telling stories about her as they had all known and loved her, laughing and crying,
and weeding the bricks which would have made her so happy.

These stories all mean something, but that meaning is one that has only taken shape
through repeated telling, interpreting, and active creation. Stories have the power to reflect
and to shape our realities, especially about our own lives. The cultural context in which
these stories originated and have been told influence both that interpretation and the
telling. While this study will focus only on a particular demographic, educated, often white,
individuals in the United States, each culture interacts with these processes differently. All
over the globe, you can find different practices and heterogeneity in how populations
encounter and experience death. In many cases, these practices include stories, whether
they be mythologies about how to best prepare for death or what happens after you die.
For people in America, there is a trend towards telling stories, especially those that are
essential pieces of an autobiography, as verbal narratives with a defined story arc (Labov 1972). These narratives can take many forms and address many topics, but generally encompass how people understand and talk about their own lives.

Individuals undergoing medical treatment in America have an opportunity, if they want it, to craft narratives around death. In places and populations where autonomy is essential, for example upper-middle class educated whites in the United States, patients are given the right to make healthcare decisions and decisions about their stories for themselves (Beauchamp and Childress 2001). This independence is, however, limited to those individuals who are able to finance their health care, either through insurance or without it.

Storytelling, as considered in this thesis, is a collaborative effort between individuals receiving formal medical care and those around them. Narratives, as discussed here, are the product of that effort. Storytelling by the subjects is as individual as the people themselves, but takes the form of an oral or written retelling of life experiences, how they impacted the individual, and how they tie together. These stories are told from the perspective of the patient and concern the things that happened in their lives. The narratives told by patients, and even their families, do not always follow precise temporal logic, but the deviations from “reality” may express a truth more indicative of who they see themselves to be (Fivush and Haden 2003). Death prompts people to tell and to interpret these stories (Cosson 2017, Didion 2005, Bevan 2003, Carroll and Landry 2010, Gawande 2014, Kramer 2015). In American culture, there are few other occasions in which an entire
event, such as a wake, is dedicated to simply telling stories about an individual. Stories, I suggest, are potential tools for individuals as they interact with death and dying.

One way that these stories can be expressed is through what I will call a life story, or a conscious and expressed version of the life review. The “life review,” or process of thinking through one’s past experiences, while observed spontaneously in older patients, has also been seen to be beneficial when prompted in young adults (Butler 1974, Borden 1989). When reframed as a type of storytelling and shared with others, this process reflects the reality that the ways that individuals can work towards finding a meaning or purpose in age and death will likely not come from medicine or science (Schneck and Roscoe 2009). Patients can also use their narratives to create an alternative sense of self (Romanoff and Thompson 2006). This ability to reinterpret past experiences in the light of current conditions can be utilized to provide aid to the dying by giving them a sense of control (Chochinov et al. 2005, Combs 1996). The work of crafting meaning through these narratives is both work that must be undertaken and an outcome in its own right (Romanoff and Thompson 2006). The stories that these patients tell themselves may work to influence their actions, identities, and experience of the remainder of their lives.

Furthermore, these types of shared stories are inherently social. At different points in the process of dying, patient, physician, and community can fulfill the roles of listener and teller. By interacting in this narrative process, each works to create meaning around the medical and personal experience they are sharing. Narrative skills, like those exhibited by individuals telling and interpreting the plot of an individual’s life story hone the ability of an individual to take in and to understand the story being told to them by another
person (Charon 2006). Furthermore, by understanding how doctors speak about the process of dying, patients can more effectively communicate with their medical care team.

The current American approach to death is increasingly controlled by medical professionals. Patients often misunderstand medical terms and even the definition of death itself now takes some medical knowledge to understand (Barclay et al. 2011). Over the last thousand years, death has transformed from being a part of daily life to a sterile, institutionalized experience (Aries 1981). As individuals becomes less familiar with the process of dying, their ability to be active in creating the conditions that surround their own is compromised. This medicalization of death has made it so that only certain individuals feel emboldened to have “control” in the process of dying. The communication that occurs during physician-patient visits further limits the ability of untrained individuals to control their stories. With scientific advances that widen the gap between patients and their doctors, patients are no longer on even footing when describing the end of life (Gawande 2014). In this world, death is not a natural and uncontrollable part of living, but something that science can direct in its intensity or progress (Schneck and Roscoe 2009, Aries 1981).

Contemporary medical training and physician socialization tend to limit patients’ ability to create their own end of life stories. In the late 1900s more scientific knowledge and technology altered how Americans understood death (US President’s Commission 1981, Branch 2013). With the introduction of the Uniform Determination of Death Act in 1981, death became not a human judgement, but a result of tests with medical technology.
Changing the medical definition of death widened the gap that prevented the average citizens from always comprehending what death meant or looked like.

The fiction of medical control, through misrepresentations of interventions and medical training further interfere with the process of meaning formation. I argue, developing doctors are encouraged to believe in their ability to “control” the pathway of a person’s life (Wittenberg-Lyles et al. 2007). That control, however, is fictional. Despite the ability of medicine to maintain the life of the body, it does not always have the power to do so in a manner that is considered acceptable by those it strives to save (Cantor 1993). A steadfast belief in medical control leads to disappointment in doctors when they inevitably cannot get a certain outcome and regret in patients when they fail to grapple with the truly uncontrollable nature of death. The illusion of medical control is perpetuated by depictions of flawless, miracle working medicine on television or in the movies. Media representations of interventions like CPR do not show the limitations of medical procedures in creating lasting benefits for patients, or even in keeping them alive (Harris and Willoughby 2009).

The flaws in medical depictions echo the toxic flaws in medical language. Adversarial medicine, or medicine and cultural attitudes that pit people against disease in a never ending battle, enforces the idea that medicine should be used to “control” a traitorous body rather than heal on a psychological and social level. To further aggravate the situation, medical language relies almost exclusively on objective fact, rather than meaningful patient narrative. For a patient, narrative may rely on more than a simple chronological and verifiable string of true occurrences. The meaning of a life does not come
from precisely how it occurred, but from the ways people talked about and interpreted it, a
reality that medical language does not effectively cope with (Bruner 1987).

This thesis will examine how patients, families, and doctors in the United States create narratives around dying. While this study does not focus extensively on narrative theory, it will explore how different people look back and tell the stories of their lives and the ways in which that storytelling affects dying. Furthermore, the thesis will focus on physicians, rather than the many other essential members of a health care team. This thesis will examine both individuals who craft their own stories as well as the stories that are told about them after their deaths. Examples of this, including fictional examples, help to illustrate these topics. The process of active storytelling can empower patients to create how they want to be remembered and shapes how families use stories in their process of grieving. I argue here that death is a process that expands beyond the biological realm into the narrative. Narratives may help to interpret and revise a patient’s life story, transforming them from passive participants in the end of lives to active creators. This thesis asserts that patients, family members, and physicians use language and narratives at the end of life as a means of attempting to understand and maybe even control death.
Individual and Family Perspectives

On an individual level, Americans who are approaching the end of their lives engage with creating stories, especially about their own lives (Butler 1974). Within this cultural context, this narrative can record their illness progression and their hopes for the future. People can tell stories about some events of the life to make a smaller scare story, or develop a large, all-encompassing “life story,” a performed and conscious version of a life review. This is because as people become ill, the need to observe themselves and to be seen as whole by others becomes more intense (Charon 2006). The drive to recognize the self is mirrored in a drive to be recognized by others (Hyden 1997). The realization that the end of life is rapidly approaching creates a deadline for individuals to complete the story arc of their lives. Making space for narratives also helps family members to form final impressions of their loved ones, even after they have died. It also pushes back against the pervasive, yet unexamined, assumption that life and the world around us is controllable (Romanoff and Thompson 2006). Individuals can be empowered to reclaim control of their life through narrative. In the absence of narrative, anticipatory grief can overwhelm a patient. Anticipatory grief is a multidimensional process undergone by patients and families encompassing both psychological, social, and physiological factors in the face of impending loss (Rando 1986). Patients and families can either be overwhelmed by anticipatory grief, or use these opportunities at the end of life to reframe their losses and tell a meaningful story that accommodates their new reality and experiences (Romanoff
and Thompson 2006, Flanagan-Kaminsky 2013). Life narratives, like all narratives, can make use of an overarching plotline, one that can benefit from a conclusion either by the patient or by others. This completeness, though not essential for everyone, may possibly help some individuals to find closure at the end of a life.

**Individual Constructions**

People use narratives to tie together the events in their life and to “articulate experiences” that they have had before death (Hyden 1997). The life review is the formal process of thinking through and reinhabiting the mental space of an individual’s past experiences (Butler 1974). By telling stories about and thinking of the path of their lives in a life review, older adults revisit the things that have happened and work through them to make them a part of a holistic self image (O’Leary and Nieuwstraten 2001). His activity can appear to observers as a movement into the consciousness of the past and perhaps even a resurgence of conflicts that were not resolved that can now be thought through and integrated (Butler 1974). Sharing a life review with others and consciously engaging with it can transform it into a life story. This process serves as a way to consider, understand, and share the feelings that an individual will have in their remaining time (Butler 1974). Life stories are a powerful tool in helping dying individuals to let go of guilt and past traumas, as well as a way to pass on values and knowledge to the next generation, recreating and reinforcing the ideals of a group (Butler 1974). The process of going over one’s life can provide aid in myriad issues that individuals can encounter at the end of their life and helps to create an overarching tale to give a life meaning, not just a death.
Patients, it seems, have a sense of their illness that may prompt this type of narration. Before diagnosis, subtle symptoms may indicate the presence of a life limiting disease and barely cross the threshold of awareness in the patient and caregivers (Campbell et al. 2016, Galvin et al. 2017). The process of narrating these experiences short of a formal life review to healthcare providers could, however, be frustrating for patients (Galvin et al. 2017). Medicalization makes it even more difficult for patients to direct these conversations in the highly technical language of medicine. The extra-medical sense has not, however, been eliminated, as Bruce Kramer in We Know How This Ends (2015) demonstrates. He is aware of his physical deterioration long before his diagnosis with ALS, detecting ominous changes to his gait before he received any medical diagnosis. In this case, we see how the process of anticipatory grief, or grieving about one’s own death, takes place outside of the medical framework (Butler 1974, Kubler-Ross 1969).

Storytelling about their own deaths allows these individuals to work through their anticipatory grief with those around them, much in the same way that their loved ones will go through grief with others after they die. Sometimes caregivers also experience this anticipatory grief prior to the death of a loved one, mourning what they will lose in the future and the functioning that the person has already lost (Holley and Mast 2009, Flanagan-Kaminsky 2013). Anticipatory grief encompasses many of the same losses for patient and caregiver: the loss of the relationship, changing communication patterns, and loss of independence (Holley and Mast 2009). By addressing this anticipatory grief with psychological care from counselors, fears about regret can be lessened in loved ones (Flanagan-Kaminsky 2013). If, however, a patient’s family is not prepared to the same
degree as the patient to encounter their end, the patients and families can be in conflict. For many people, according to Elisabeth Kubler Ross, coming to terms with their own stories and sharing that peace with their loved ones is essential to achieving acceptance (Kubler Ross 1969).

As patients engage in the process of narrative formation at the end of their lives, they are creating a story that directly influences the types of grief their family members are likely to experience after they pass. In medieval tales, in an individual’s death was calm, their family was expected to mourn wildly enough to express proper despair (Aries 1981). Mourning is a process that hinges upon the experience of the person dying. In the times that have come since, the expectations placed on mourners have greatly diminished but the tale they tell is no less influenced by the manner of death of the person being grieved. Patients who experience a “good death” as determined through their perceived pain are significantly less likely to leave behind caregivers with PTSD (Garrido and Prigerson 2013). Patients who construct narratives that de-emphasize pain they might be experiencing and who may use those narratives to come to terms with their death, are more likely to experience the good death the Garrido and Prigerson (2013) described, and therefore to have positive impacts on their loved one’s quality of life after they are gone.

The Death of Ivan Ilyich, an over 200 year old novella from Russia, helps to highlight some of the tensions that narrative creation around the end of life explores. The piece further provides a fictional example of one man’s story. Despite the age of the piece and the distant culture it represents, the relevance of Ivan Ilyich tale is undoubtable. The novella is still taught in US medical schools as a part of the introductory curriculum and continues to
impact modern thinking about how medicine interacts with death (Gawande 2014). In The Death of Ivan Ilyich, Tolstoy explains the character’s life story after introducing the fact of his death. Although we know that all people’s stories end in death, to start the novella this way is shocking. Ivan Ilych’s impending death changes how we see him and how he sees himself. The character notices the change in his identity and fails to recognize himself; noticing the contrast between the man depicted in the looking glass and the portrait of who he still considers himself to be (Tolstoy 1886, p. 25).

Furthermore, the urge to “think it all over” from the beginning of his illness and determine the root cause is a desire to create a narrative around that illness, to harness and understand what it is and what it has done to him (Tolstoy 1886, p. 26). The end of Ivan Ilyich’s life is made tortured by the inability of those around him, and at times his own inability, to understand and recognize the process of his death. The stories he tells to himself about how he fell ill and about his childhood show him reviewing the events of his life. Ivan Ilyich’s “inner voice” prompts him to consider his “pleasant life” (Tolstoy 1886, p. 41). The hopelessness that he experiences in retrospect and the regret that he feels are real and important parts of the story he creates about his life, but his ability to reframe his unease and dismiss it (p. 42) are equally a part of his story.

**Authorship and Control**

People's' stories are based on their own decisions about what narrative to create but also must recognize their physical body. In instances of severe illness, patients often offer two divergent stories of the “self,” one of their physical body and one of the person...
they consider themselves to be. The clues provided through the body are indistinct, however, and require interpretation (Charon 2006). Individuals can misinterpret these signals or choose to deny them. People exert mental “control” over the physical conditions that they cannot control.

Patients are able to be autonomous in a variety of ways. However, narrative autonomy, as Casado da Rocha postulates in his 2014 paper, is the most influential. Narrative autonomy, or ability of individuals to create a shared story that encompasses both their past and their future, demonstrates the power of storytelling and narrative creation in aiding patients (Casado da Rocha 2014). Whether patients require or even desire control in their narratives, however, is variable. Novel therapeutic methods, for example, dignity therapy, apply the concepts of narrative medicine to provide a form of psychosocial care for individuals nearing the end of their life. Dignity therapy prompts terminally ill patients to reflect upon the ways in which they would most like to be remembered (Chochinov et al. 2005). By leaving behind a concrete document to carry their legacy forward, also known as a generativity document, dignity therapy attempts to address the underlying anxiety of facing one’s end with no certainty about a continuing impact. A generativity document can take on many forms, from “self-boxes,” “memory books,” “life maps,” or anything else that a counselor can help their client create to solidify their impressions of their own life (Caldwell 2005).

While dignity therapy may help patients seeking a greater sense of control, for those who want to feel less control, there are still options. By foisting ultimate power to God or fate individuals facing their illness can lessen the burden that they may feel (Young and
Rodriguez 2006). By creating a power structure and driving force within the narrative that pushes an control from within the patient to a larger body, the patients can not be accountable for what has happened in their lives. This method can be employed by patients struggling most to accept their diagnosis or those who have embraced the idea that to die is to lose in the contest against cancer or illness. Alternatively, patients can work to maintain autonomy in their lives through reframing their narratives in ways they can control. By working towards a balance between “resistance and acquiescence” patients consider themselves to “persevere” in a balancing act between the mind and body (Lloyd et al. 2014). This perseverance and the drive to be an author of one’s own narrative allows a “continuation of individual identity” (Lloyd et al. 2014).

In Wt (1999), the one-act play by American playwright Margaret Edson, the central character is Vivian Bearing. Dr. Bearing is an expert on the English poet John Donne and provides a fictional account of an individual meeting the end of her remarkable life as a result of terminal ovarian cancer. The narrative that she begins to construct is one exclusively about work connections, but it increasingly yields to one about interpersonal connections. The first interaction shown in the play, between Bearing and Ashford, her doctoral mentor, is a professional critique of a piece of work that Bearing has submitted; on the part of Bearing, more a cold exchange between colleagues than a friendly encounter (Edson 1999). Their final interaction, however, is that of a mother and a daughter, someone providing comfort to another person whom they care about. Vivian’s need, in that moment, to steer the topic away from their professional interactions surrounding Donne show her turning her life’s narrative away from the cool and impersonal emphasis she has
historically placed on her work. The change in Vivian’s attitude that comes about through her reflections through the play is yet another example of those approaching their death, even in fiction, attempting to reframe what their life has meant.

Arthur Frank argues in *At the Will of the Body* that those who are critically ill are enabled as well as compelled to think about what their life means in different ways (Frank 1991). Frank himself was prompted to do this when, in the period of two years, he suffered a heart attack and was diagnosed with cancer. As a professor and sociologist, Frank encountered his illnesses and decided to write about them, posing his entire book about illness in the form of a narrative. The urge to “narrativize” and create vignettes of these traumas helps him to extract meaning from them using his background and training. Part of his urge to write the books, was a response to the pressures that he experienced as a patient.

Within the medical system, patients are prompted to adopt a new language of “medical-ese” that can, through forcing patient experiences to be expressed in a medical way, take away some of the drama and imprecision that is a part of normal life (Frank 1991). A clear example of this takes place in the diary of Tim Bevan, a man in his mid-thirties who chronicled life after his leukemia diagnosis in a series of emails to family and friends. His transition from independent and adventurous documentary camera-man is clear as his hobbies, like drinking wine, yield to the demands of aggressive cancer treatment. Increasingly, through the course of his illness, he begins to talk to his family and friends about his situation as more medical, rather than with the personal touch with which
he began. Rather than speaking about his passions, he begins to explain his life in “medical-ese” (Bevan 2003).

Patients often find meaning through the creation of hope, whatever that may mean to them, whether it be hope for a cure to what ails them or the hope to be free from pain. Individuals who are dying can create meaning by believing that their suffering will eventually reap benefits for them if they can endure it for just a bit longer (Kubler-Ross 1969). This helps to give patients creating the story at the end of their life a mission which can help them maintain their spirit (Kubler-Ross 1969). Patients are counseled to commit fully to the hope in treatment (Edson 1999). Treatments are described as inevitably leading to benefits. Even in Bevan’s story, his last emails to family friends are marked by hope that remission is possible, despite increasingly discomforting mentions of infections and lost feeling within his legs (Bevan 2003). Stories, by providing patients with the ability to revise and reinterpret, are a fundamental way for them to express and create hope. Patients can use their past experiences in the form of stories to frame their hopes and expectations for their family and care providers, and to generate new ones. One of the shortcomings of the current medical system is its insistence that the greatest thing for the patient is for them to avoid, in other words postpone, dying. Sometimes this delay leads to far worse suffering than dying would have brought.

Narratives serve multiple purposes for individuals who are dying, giving their lives a sense of purpose, giving their current state a sense of worth, and giving them a way to control what is happening about them, rather than allowing things to happen to them. Narrative helps to accomplish the imperatives that all humans have in their lives: wrestling
with mortality. Stories, furthermore, do not have to mortal, while humans do. Even after a person is gone, their story has a way of sticking around, even if only for one more generation. Keeping the dead alive through storytelling further serves to maintain their connection to our lives (Didion 2005).

Communal Nature of Narrative

Patient narratives create a collective experience out of an individual one (Hyden 1997). Patient stories about their lives are most often intended to be shared and are most impactful when they are told to family members or those the patient cares about in an exchange of joint meaning creation. The trade, in essence, is the value of one life’s story in exchange for the ability to have an impact beyond the time frame of their mortal life. Even when a life is not ending, stories of the self have the most meaning when they are shared (Fivush and Haden 2003). Poetically, patients further use their relationships with others and the stories that they tell them as a means of maintaining an ability to make autonomous decisions and narrative creation (Lloyd 2014). Narrative can be the final space in which individuals can exert control over what they feel happens to them. Yet, because these stories rely on the participation of others, this autonomy is born of and dependent upon others.

A prominent fear among the dying in the United States is that of being forgotten, or a loss of social role and identity (O’Leary and Nieuwstraten 2001, Mikulincer and Florian 2008). In crafting conversations in which patients are assured that they will be remembered through shared narratives, those types of fears can be assuaged (Hedtke and
People form their identities through the communities that they are a part of, and in turn, may benefit from input from that group as they culminate their experience of life (Bruner 1987). Personal narratives, ultimately, have the ability to alter a culture and reflect it (Bruner 1987).

Patients in American society often undergo a social death prior to their biological death (Lloyd 2014). In part this death is because they are no longer recognized as “like-me” by those around them (Taylor 2008). Care is a way to acknowledge and, to an extent, recognize another individual. The interactions that take place around narrative creation help to fuel this recognition. Additionally, forming a story that can be used to identify and reinforce an individual’s sense of self allows them to recognize themselves. A community created through the shared remembering of a narrative allows a group to form and solidify. Shared memory of these narratives is the mode through which we hold together our deepest relationships together (Margalit 2002).

This kind of interaction can be seen, even in fiction. Ivan Ilyich of Tolstoy (1886) also clearly exhibits a desire for his condition to be recognized. In Chapter 7, he admits that the deception of his wife and daughter “tortured him” and that in failing to acknowledge the gravity of his condition, their actions undermined how he was experiencing his death. Gerasim, a servant in Ivan Ilyich’s household, provides simple forms of care, like holding Ivan Ilyich’s legs on his shoulders to help with the pain and speaking with the dying man. Unlike the family and healthcare providers bound by decorum, Gerasim recognizes that one day, he too will be in this position of vulnerability and terminality and that the favors that he does for Ivan Ilyich are no more or less than what he would want done for himself.
(Tolstoy 1886). Just as Ashford can provide a comfort to Dr. Bearing by sitting in bed with her while reading, so too can Gerasim can provide comfort to Ivan Ilyich by holding his legs. These simple physical acts that transcend culture are special in that they operate outside of the rules of decorum that regulate professional interaction. These acts of caring and recognition are transformative. They turn the story told about an individual into one told in conjunction with them. Human touch provides a bridge between two individuals and rather than each engaging in a separate action, they are then doing that action together.

**Posthumous Narrative**

Narratives create continuity to life after death and help to assuage dying individuals’ anxieties about death. These types of stories are distinct from a life story but navigate a process that is also essential. In finALS, an online journal of dying with ALS, Vivian Connell, sends off her reader with a last post of “thank you’s” before she begins palliative sedation. This pattern of thanking those involved in one’s life is also present in Tim Bevan’s diary of dying from leukemia. These two ordinary individuals are using technology as a way to amplify the social circle with which they are experiencing their deaths. Individuals cannot tell the end of their story, and autobiographies cannot be complete, they simply end (Fivush and Haden 2003). The uncertainty of dying means that any final conclusions must be completed by those who outlive the autobiographer. Because all humans die, storytelling helps maintain the meaning of our lives after they are over.

This has not always been true to the extent that it is today. Early tombstones show an anonymity in death, as typified through unmarked tombstones, which yielded to
inscribed dates of birth and death on tombstones and eventually the public announcement of deaths via mediums like obituaries (Aries 1981). The transition to more recognition in death is a way for a memory of a person to persist, even after the person themselves is gone. These inscriptions, obituaries, and narratives have taken on new forms as recognition of each other’s’ lives has also changed. Now, individuals are as recognized in their deaths as they are in their lives. With memorial facebook pages kept for years after someone has died, the trend of recognition in death has become more common (Kern et al. 2013). Death recognition has permeated online communication, showing the importance of shared experience in mourning and the essentialness of community in death and dying narratives (Carroll and Landry 2010). As community dynamics change, so do the ways we interact with those who are dead and dying.

The post-mortem practice of storytelling about individuals continues this effort to craft a meaning for their life as a personal experience. In her narrative about grief, The Year of Magical Thinking (2005) by Joan Didion is an extended practice in this process of repeated story telling. In the book, Didion reflects upon the year immediately following her husband’s unexpected death and daughter’s near death illness. In crafting narratives, family members can make even an unexpected death seem expected in order to better cope with the loss. As Joan Didion observed in The Year of Magical Thinking (2005), just being addressed by a social worker in the emergency room was enough for her to know that her husband had died (Didion 2005). The work that she puts into telling the stories about her deceased husband are her way of coping with that grief and putting meaning into a loss that happened so fast she had no way to cope with it prior to his passing. The stark divide
created before the death and after the death is further observed by Didion as something abrupt and sudden (Didion 2005).

Families use stories of their experiences with the deceased to cope with an event that is always shocking, no matter how long they “saw it coming” for. By looking back over losses, these shocking experiences can take on an expanded meaning. Didion (2005) describes her grief as a vortex, one that seems to suck her further and further into retroactively looking at her life with her husband. Her work as storyteller is mourning, and her grief demanded her attention (Didion 2005).

Stories can also serve as a revision of our impressions of those who have been lost. As Didion puts it, it is a way of substituting a highlight reel (Didion 2005). The idea of a highlight reel is also present in the Epilogue to When Breath Becomes Air, the story of Dr. Paul Kalanithi, a young neurosurgeon as he died of lung cancer. In the Epilogue, Kalanithi’s wife makes it clear that she has made the explicit decision to include the information about their marital struggles in the book, intentionally bucking against the trend that she recognizes. She does, however, still decide to include her encouragement to her daughter to always know that her father was a great man. This need, to ensure that the person she loved is remembered kindly, is pervasive across narratives, and ultimately, an appropriate way for people to cherish their memories of a loved one.

**Final Chapters and Epilogues**

Death, no matter how long a person has been suffering or his or her own views about an afterlife, is a conclusion. The need to craft this conclusion drives much of narrative
creation at the end of life. In *W;t*, Vivian observes these narrative tendencies in her own construction of the play. She observes, disappointedly, that there was no time after her hastening decline to create an artful conclusion (Edson 1999). The parallel structure created by citing the flawed form of Donne she critiques earlier in the piece further demonstrates the need to wrap-up. While fictional, this writing is a heavy-handed representation of the poetic meaning and the wrap up that humans try to find in their lives. By tying together loose ends of narrative and referencing back to earlier memories, people can create a collective, and sometimes revisionist view of their lives (Butler 1974).

An overarching narrative can also help to create a sense of time about a timeless period, or bring comfort. As Edson observes via Vivian in *W;t*, death “came so quickly after taking so long” (Edson 1999). This suddenness, even in the face of terminal illness, forms a common thread between the narratives of dying patients. In Tim Bevan’s diary of his leukemia, his wife observes that his rapid decline “happened so quickly” (Bevan 2003); in Paul Kalanithi’s book, his wife observes that even though his strength “waned over [...] months,” his “health was declining rapidly” (Kalanithi 2016). Patients who are dying, and those who care for them, seem to be surprised about the patient’s death with odd prevalence, even when the patients are aware about the approaching end of their lives. This shock is, in part, because physician estimates about how long patients will continue to live are rarely ever correct. Patients and physicians work together to feed into the denial of imminent death and create an alternative plot in which patients will fully recover (Hak et al. 2000). Even Tolstoy recognized this propensity, as far back as 1886. Physician estimates skew towards the optimistic, with approximately 83% of physician predictions estimating
that a patient would live longer than they did (Parkes 1972, Barclay et al. 2011). Medicine often seems able to divert death every time, until the last time when it fails. Kalanithi’s cancer goes into a remission, allowing him to plan to start a family, but comes back just as quickly and this time worse than ever. Death and disease reveal the profound lack of control in human hands by making in clear how quickly things can fall to pieces (Frank 1991).

By working to create a conclusion post-mortem, family members can add some finality. The conclusions provided, in Bevan’s diary (2003) and Kalanithi’s reflection (2016), by the women who loved these men who died of cancer, are an attempt at conclusion and convenient wrap-up to a story that does not have one. Their attempts at creating this closure are reactions to their own loss, reducing ambiguity to facilitate their grieving (Boss 1999). Each woman tries to provide both context for the passing of the person that she loved as well as to cope with her grief.

Individuals outside of the medical field use narratives and language to understand, reframe, and craft life stories. Patients and their families both rely on these narratives as tools at the end of life to claim and maintain a sense of control at a time when medical thinking and illness control so much of what happens. Narrative is how people can make sense of those things that are inherently non-sensible (Eggly 2002). The end of life prompts these storytelling habits because it puts us in conflict with the unquestioned assumptions that we have control over our own lives (Romanoff and Thompson 2006).
Medical Perspective

In the American medical system, physicians often take on a leadership position in the medical experience of dying. In modern American medicine, however, that leadership rarely extends beyond physical treatment. Doctors today connect to their patients less, as the pressure to see a greater number of patients in a day intensifies, and the advent of new practice models challenge the idea of one constant primary care provider (Linzer et al. 2015, Hawkins 2012, Branch 2014). Physicians now spend almost one sixth of their time working on administrative tasks rather than engaging with patients about their needs or narratives (Woolhandler and Himmelstein 2014). Time constraints and medical culture prevent physicians from connecting with their patients as they attempt to elicit facts and inadvertently interfere in narrative sharing (Romanoff and Thompson 2006, Wittenberg-Lyles et al. 2007). Other members of the health care team, such as nurses, also lose this ability, especially in long term care facilities where 1.2 million members of the aging US population reside (Administration on Aging 2015, O'Leary and Nieuwstraten 2001).

Further distancing patients from the ability to determine their own stories at the time of death are shifting cultural tides. Medical authority on death has come to control how we define death and where we encounter it. These tensions, between patient need for control and the power of the medical system, make the medicalization of death all the more
problematic. Issues that are only biomedical can be dealt with in a more controllable setting --the hospital. As medicine took control of the dying process, dying people began to be treated as patients in a hospital, rather than community members in the home (Aries 1981). In these settings, psychosocial care takes the back seat and the illusion of control under the biomedical model dominates (Cole 1992).

Physicians, especially, fall prey to the desire to exert control over the dying process (Wittenberg-Lyles et al. 2007). This drive rests on an assumption that is instilled in providers over the course of their medical training, that authority over a patient’s life falls under their control (Wittenberg-Lyles et al. 2007). This assumption further rips control of the patient’s narrative away from them, giving power almost entirely to their illness and their health care provider. Doctors visits replace other daily activities and hospital inpatient life interferes with everything else. With the introduction of illness and the prospect of loss, patients lose control over their narratives. The intervention of physicians as the new power figure prevents the patients from regaining that authority (Romanoff and Thompson 2006).

**Inaccessible Definitions of Death**

Death in the medical setting has grown from what historically was an instant to a long process with myriad interventions. By lengthening and adding subdivisions to our interpretation of death, doctors are needed to interpret what it means for a person to be dead (Aries 1981, Hak et al. 2000). The concept of a good death, has remained difficult to define, in part because of the discomfort of health care professionals in confronting such
conversations (Donnelly 1984, Cipolletta and Oprandi 2014). The expansion of treatment options has created the idea of that there are seemingly endless interventions to be pursued (Hak et al. 2000). Physicians modify the dying story by allowing, reinforcing, and encouraging a “recovery plot” (Hak et al. 2000). In American society, this plot is one the doctor directs and in which patient participation is implicitly assumed. Under the recovery plot, patients and their doctors collude to perpetuate the increasingly unlikely outcome of a full recovery. One effort to stop this narrative short came in the Uniform Determination of Death Act in 1981. This Act established two criteria for physicians to declare a patient medically dead: the irreversible ending of either circulatory and respiratory function or whole brain function (US President’s Commission 1981). The added variable of ending life in a way that can only be interpreted by medical personnel shifts control further into the domain of medicine. Despite the benefit of being able to declare patients who have no chance of recovery, brain and medically dead, families have still not been able to break out of the recovery plot. The old and easily identifiable signs, such as cessation of heartbeat or respiration, are no longer sufficient or even necessary for a physician to understand death, but may be very important to a patient’s family.

Physicians are hesitant to talk about end of life care options, in part because they are afraid to talk about alternative definitions of death and the idea of a good death (Barclay et al. 2011, Momen et al. 2012, Cipolletta and Oprandi 2014). Physician fear leads to following the patient’s lead and to continuing to buy into the recovery plot. Conversations that may deviate from this plot are those that surround the creation of advanced directives and do not resuscitate orders (DNRs). Alternative names for advance
directives have been bandied about in the past few years to reflect more realistic outcomes from the direction they contain. In reality, few patients have long term benefits from efforts to resuscitate them (Harris and Willoughby 2009). New terminology, like “Do Not Attempt Resuscitation” show more realistically the power of medicine to stop a process once it has begun to occur (Sokol 2009). Another proposed alternative is the Allow Natural Death (AND) form (Sokol 2009). While the intention in creating these new types of consent forms is good, the implicit assumption it reflects is that it is necessary for health care to “allow” death. This assumption demonstrates an underlying hubris in the medical system.

**Context and Content of the Physician-Patient Visit**

The tensions evident in the difference between medicine and colloquial language come to a head in the physician patient visit. Doctors have generally encouraged use of the Labov-Polanyi narrative format (1972, 1985) in their interviews with patients, relying on temporal junctures, topically relevant and coherent content, a smooth transition into the conversation, strictly chronological structure to develop an understanding of the narrative the patient is trying to share (Eggly 2002). This prescriptive model of narrative, while efficient, does not allow for models of communication that may be more natural for the patients. As pressure builds up in the medical system to expedite the process of delivering medical care, the pressure on physicians to use more efficient communication heuristics will only grow (Haidet and Paterniti 2003).

The most basic communication in a medical visit is the taking of a medical history. This process all too frequently lacks the concept of shared presence. Shared presence is the idea of a trust, respect, and mutual knowledge between physicians and patients that can
help healing occur more easily (Ventres and Frankel 2015). Clinical communication in the physician-patient relationship is nurtured through narrative communication, a type of biopsychosocial care. Interpersonal skills and building relationship frameworks are bolstered through narrative communication and are integral components of shared presence (Ventres and Frankel 2015). These skills can be employed by physicians who are able to integrate both a biomedical and a patient narrative in the patient’s medical history (Haidet and Paterniti 2003). A skilled physician can employ shared presence to work to construct a joint medical history, incorporating the narrative of patient and supplementing it with their own knowledge and conclusions (Haidet and Paterniti 2003). Conversely, if physicians convert the language of patients into their own, they take away the words of the patients and change their narrative into a medical one. This propensity is in part a symptom of a medical system that dehumanizes everyone-- medical professionals included (Donnelley 1984).

The evolving character of the hospital has also had an impact on narrative around deaths and the meaning contained within them. Furthermore, as the medical profession has become unemotional and excessively controlled, even medical professionals have become uncomfortable with a messy death interfering with hospital routine (Aries 1981). In the framework of death and life narratives, this setting both directs and reflects the forfeiture of patient direction of narrative to the physician. Hospitals as a super controlled setting are now where we may consider a type of normal death to occur (Aries 1981). This transition shows the amount of control that many Americans now expect to have over death. Hospital routine between providers fails to make space for the dying process, the dramatic deaths
that may be meaningful or necessary for patients disturbing the order that providers have attempted to create (Aries 1981). Emotional control, on the part of physicians and patients, is tantamount to smooth functioning of these massive and efficient structures. The American fee for service model places pressure of physicians to treat in this way (Linzer et al. 2015). Physicians are compensated based on the number of patients they see or procedures they perform and therefore need to move their conversations with patients as quickly as possible to meet goals for the number of patient visits on a given day (Linzer et al. 2015).

**Physician Training**

Physicians use of narrative is shaped by their medical training process as well as the language that they use to frame narratives with each other. As doctors in training learn what it means to be full participants in their profession, they adopt the language of their superiors and peers, reframing how they see their patients despite the harmful language it perpetuates. Providers sharing narratives with each other is also an important way for them to manufacture and share their own values, identities, and sense of social role based on how they take part in medical events and the situations they take part in at work (Wittenberg-Lyles et al. 2007). These narratives can work as a template for new providers working through their own initial encounters with the dying process. By providing a scaffold for others to understand their experiences, providers do a service to each other and themselves. Furthermore, the process of interpreting and interacting with narratives can help alleviate some of the stresses on providers that lead to burnout (Kraser et al. 2009).
The drive within American medicine to control and to fix, especially among physicians who are culturally viewed as near miracle workers can supersede the needs of the patient. This tension is present as early as medical school when students are graded and critiqued based on how well they can intervene in or treat diseases and symptoms in their patients (Wittenberg-Lyles et al. 2007). Interventions that treat and fix are deemed superior to those that simply facilitate coming to terms with one’s own mortality. Furthermore, doctors are taught to view sickness as an enemy to be conquered by all forceful means necessary (Hodgkin 1985). The way that physicians talk about their patients and their patient’s care follows this story and pattern: a battle to fix a failure. Further, in an analysis of physician narratives, Wittenberg-Lyles found that physicians overwhelmingly described the end of life treatment of patients in this way.

The iterations of teaching in medical school and residency perpetuate patterns of detachment. The process of medical socialization focuses on interventions with the implicit notion that intervening in the process of life is the power of the doctor (Wittenberg-Lyles et al. 2007). When evaluation of students hinges on the efficacy of their interventions rather than the quality of life their patients attain, caring takes a back seat, even at the end of life (Wittenberg-Lyles et al. 2007). As the physician’s feelings of obligation towards fixing and control controlling takes over, the real needs of a patient can fall by the wayside (Wittenberg-Lyles et al. 2007).

Rita Charon (2008), in her seminal book on narrative medicine talks about the creation of parallel charts, in which the medical students in her rotation are required to create both a personal, journalistic chart for their patient and the more traditional
biomedical chart. These charts showed her residents taking on the work more often adopted by palliative care providers. As Romanoff and Thompson, 2006, state palliative care providers play an especially important part in the process of patients and families working to build narratives and meaning together. Through the active reconstruction of life stories, the patients forge new understanding and new meaning for themselves and their providers. While it may seem as if this process of narrative formation is always beneficial, however, in some limited cases, medical students being taught how to co-construct narratives with their patients found that it created a distance between them (Chretien et al. 2015). Emotional intimacy between patient and provider that feels or is forced can negate these efforts at improvement. Doctors in training should be taught the skills that will serve them and their patients, by making them more empathetic, genuine listeners, and when they need to delegate to other members of their team.

Doctors, despite being encouraged to construct illness narratives with their patients have not always had a strong definition what constitutes a narrative. In Eggly 2002, the author advocates for an expanded view of what constitutes a narrative to account for the idea that both patients and providers work together in a medical interview to construct the full illness narrative. This view helps to account for the joint venture of narrative and the community it helps to build between two individuals. Absolute truth, a verifiable string of factual events, should not the essence of the conversation because both patient and doctor bring their own background knowledge and understanding into the conversation.

Within certain domains of medicine, the space for narrative creation is even more essential. Palliative care providers, in particular, bear much responsibility to facilitate
communication for patients and families to reform a story in the context of the illness (Romanoff and Thompson 2006). By reinterpreting stories after an illness has begun, patients get the opportunity to redefine and create new but still meaningful narratives. Even in palliative care teams, however, this does not always happen. Each practitioner is expected to comment based on their area of expertise which can, in turn, limit their contributions (Romanoff and Thompson 2006). On an interdisciplinary team, deeply understanding the role of other providers and being less rigid in how they interact with patient’s problems, doctors could better serve their patients.

Adversarial Medicine

Medical narratives demonstrate their drive for control in part through the use of adversarial language and depictions of battle (Donnelley 1984, Hodgkin 1985). The way physicians have come to speak about death has also pervaded the colloquial mentality. The idea that aging is a failure has taken over discussions on death and dying in medical settings, rather than these processes being natural and appropriate (Vincent 2007). The message that at all costs doctors can prevent death has led to the patient perspective that they can somehow avoid it (Didion 2005).

The idea of war in medicine is nowhere more pervasive than in the language of the fight against cancer. Popular media paints a picture full of survivors, foot-soldiers and a dark looming enemy (Frank 1991, Leaf 2004, Garrison 2007, Marchione 2017, Perlin 2017). Fighting disease is depicted as a Greek tragedy, full of the heroic figures that come with that characterization (Leaf 2004). Public policy interventions, most notably the
National Cancer Act of 1971, has further been characterized as battle against disease, rather than an effort to alleviate suffering (Nixon 1971). Patients are encouraged to create a battle plan rather than a care or treatment plan (Frahm 2000). While this process may be motivating, and even inspirational for some, the lack of alternative metaphors through which to understand the experience of disease may leave some patients wanting (Frank 1991, Garrison 2007).

The language of a fight for health and life reflects the American mentality that being autonomous and individualistic is essential, and that bodies are personal property, to be controlled and enjoyed (Garrison 2007, Schenck and Roscoe 2009). This mentality leads patients, and even providers, to believe that when people die it is because they have actively chose to do so and that that choice is within the control of medicine (Schenck and Roscoe 2009). This mentality extends far, even to cosmetics companies and widely into the public sphere (Vincent 2007). Even in obituaries, patients are characterized as having lost out on a long battle (Schenck and Roscoe 2009). This creates a terrible correlation in forcing the line of thinking that when a person dies, they and their weakness are to blame (Didion 2005). The confusion that society faces in coming to terms with these losses stems in part from how disease interrupts assumptions about a controlled world (Romanoff and Thompson 2006).

The battle of active medical protagonists set against Evil in the form of disease or age takes place on the battlefield of the patient. As any battlefield, these patients bear much of the harm done by this confrontation. By creating a fight rather than treating illness as a natural part of life, medical systems alter the narrative of patient life to be in combat to
wrest control of their bodies away from their illness with the aid of medical professionals. Language throughout medicine reinforces this perception. For example, a patient is noncompliant to battle orders issued by a physician rather than simply missing doses of medication (Donnelley 1984). This language also minimizes the real human suffering that can occur in medicine (von Elm and Diener 2007). When society and medicine speak about “collateral damage” rather than the impacts of the devastating side effects of chemotherapy, they insinuate that those powerful consequences are simply sacrificed to the higher goal, winning the war (von Elm and Diener 2007).

These changed narratives tear control away from patients through the language being used to describe their illness. If battle metaphors focus on doctors as heroes and illness as attacks, patients are forced to watch the battle play out on the field of their body, and, in the event that they choose not to partake, to be judged for an unwillingness to engage.

**Medical Reliance on Facts**

A major divide between personal narratives and medical narratives in certain populations in the United States is medicine’s exaggerated reliance on facts. While facts are important in medical communication, the ways that people find meaning as they age veer far from medical and objective tools (Schenck and Roscoe 2009). When physicians strive to be objective, and therefore more professional, their conversation tend to exclude the patient. As Arthur Frank put it, when patients are asked to speak in medical settings, they are asked to remove their thinking mind from their body and talk about it as if it’s a separate entity (Frank 1991). Physicians themselves observe this tension, and in striving to
balance both scientific and humanistic treatment, must balance their need for objectivity in evidence based medicine and the aid provided through personal connection that may require less strict adherence to facts (Wittenberg-Lyles 2007).

Medical practice relies on a belief that understanding the world through an objective scientific lens is the only relevant mode of understanding for a doctor (Donnelley 1986). Emotions are the antithesis of this and a doctor is considered effective when they direct emotional tone in every situation, becoming emotionally isolated themselves (Hodgkin 1985). The importance of controlling emotions by eliminating narrative is essential to maintaining solely-fact driven medicine rather than allowing realistic emotions to become a greater part of the medical process.

The attempts of physicians to elicit more factual narratives may actually hinder their efforts at meaningful communication with patients. Physicians trying to elicit facts rather than understand a narrative may exhibit signs of narrative disinterest. Narrative disinterest can occur if when a listening individual either breaks into or changes the direction of a story in search of objective truth, rather than the storied account that a patient is attempting to share (Romanoff and Thompson 2006). This process disrupts the essence of the story that the patient is trying to convey and communicates to them that their experience is not as important as the objective truth the provider is trying to ascertain (Haidet and Paterniti 2003). Rather than recognizing the experience of the patient as whole themselves, the provider is trying to twist the story to what matters in their chart.
In conversing about patients, objective lab tests are given precedence over narrative and patient experience (Donnelley 1986). These test, however, can be misinterpreted and are subject to biases in how the physicians may read into them (Blumenthal-Bardy and Kreiger 2015). The idea that these facts are more essential than patient experience or belief about their own disease is a pervasive and disregards what may at times be the most important parts of treatment. Medicine should be crafted as more than just a collection of scientific knowledge, but the further use of that knowledge with non-scientific skills that are still relevant to the process of healing (Donnelley 1984).

**Physician Assisted Death**

Questions around patient narratives have implications beyond individual medical decisions. Physician assisted death, or the practice of doctors providing a prescription that aids in someone intentionally ending their life, is one area in which narrative creation can have a large impact (Terminology of Assisted Death 2017). In the current debate about physician assisted death, narrative techniques provide an opportunity to address some patient concerns in a new way. In Oregon, the drive to pursue physician assisted death was most often a means to regain autonomy as a dying patient and to avoid a loss of control over the body (Chin 1999, Sullivan 2000). While pain was a factor 43% of patients who pursued physician assisted death in Oregon in 1999, loss of independence and desire for control were more prevalent, impacting 57% and 53% respectively (Ganzini 2000). Despite more psychological distress in patients, physicians responded to the requests with
biological remedies, opting to control pain and physical symptoms in 30% of patients but prescribing only 18% with antidepressant or antianxiety medication (Ganzini 2000).

The understanding of these drives as related to physiological factors, rather than psychological ones, is symptomatic of the issues previously discussed. Patients encountering a medical system that is only enabled to address biological problems are likely to seek, and likely to receive, biological solutions. Doctors who are untrained in addressing psychological needs may be less equipped to help patients deal with these struggles and more likely to support a hastened death for the patient (Kelly 2004). This attitude impacts patients, in turn making them more likely to pursue a hastened death (Kelly 2004).

The drive for control among terminally ill patients who choose to pursue physician assisted death is understandable. These patients have gradually been deprived of their ability to direct their life, first by their disease, and then by the medical system. With physician assisted death, someone without control of their diagnosis gets to decide where and when they die. But what if that same drive can be accomplished by giving individuals the right to author their own narrative? Rather than letting someone be the architect of the moment at which they die, narratives give them opportunities to understand and contextualize their experiences. By freeing space for a patient to construct his or her story, both about living and about dying, they are able to imbue that story with a meaning and reclaim some autonomy that terminal illness has taken away from them (Romanoff and Thompson 2006). Narratives can give patients their independence back.
The medical system in America is broken when it comes to patient narrative. Doctors are particularly prone to language that reflects and enforces the medical idea of control over death as essential. The chasm in understanding and interpretation between medical and non-medical perspectives creates a boundary for understanding and communication. While there is clearly room for improvement, there are promising opportunities to grow and provide better care to patients as they approach the ends of their lives. Policy changes, cultural changes, and intentional efforts like dignity therapy can help to improve patient care and shift physicians to a healthier paradigm.
Conclusions

With the power of modern medicine to sustain life, death has been reinterpreted and reframed. Patients recognize the internal drive to relate and revise the stories of their lives, looking back through past experiences in a life review or life story. Through acting as authors of these stories, they can strengthen relationships that allow them to impact others, even after they themselves have died. Family members can use stories to create conclusions that otherwise would not be possible. Conclusions do not come naturally, even though death does. People continue to impact us and we can continue to learn from them through the stories that we tell after their deaths.

Even as the medicalization of dying changes what death means, medical professionals can help patients and families regain control. In something as simple as a medical history, physicians have the opportunity to create change for their patients by working on a joint narrative, rather than solely a medical one. Doctors can empower patients to craft their own narratives giving them a sense of control in a process that is ultimately completely out of their hands. To create these changes, physician training must adapt. New forms of training have the opportunity to provide the next generation of
doctors with an expanded tool-box, one that does not enforce toxic ideas about adversarial medicine and that is flexible enough to include new narratives.

Narrative has, to a large extent, been removed from medical practice, but a change in language offers the promise of helping to redress this issue. Choosing to speak about medicine as a collaborative effort to craft a narrative relying on equal participation from patients, physicians, and family members can help to build a new framework for empowered care (Hodgkin 1985). This change could alleviate a burden that plagues doctors and bring peace to patients.

Narrative can be essential for some patients at the end of their life when their presumed autonomy has been taken away by disease and circumstance. People, especially patients who have lost control over their lives, want to be the authors of their own stories. The opportunity to tell their story transforms patients from passive individuals to active participants in the creation of their life’s narrative description. Stories morph patients from the objects upon which medicine acts to the creative force behind their own lives and even deaths.
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