

**“Dying is not easy, but it needn’t be this hard”:  
Contemporary Narratives of Good and Bad Deaths**

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The 21<sup>st</sup> century has seen a surge of discourses critiquing discussion of and approaches to end of life in the U.S. In this dissertation, I perform a conceptually-oriented rhetorical analysis of the concept of the good death in narratives published in ‘The End’ (2015-2016), *The New York Times* op-ed series about end of life, and Atul Gawande’s bestselling book *Being Mortal* (2014). Grounded in rhetorics of health and medicine, I conduct an in-depth analysis of narratives of patient deaths told by healthcare practitioners in order to uncover images of good and bad dying constructed within, some ideological investments of those images and the historical contexts that shaped them. Taking seriously the idea that public narratives surrounding health and medicine impact how medical situations are approached, I argue that a narrative shift away from decision-making and the dying person as primary agent at end of life may shift standards of judgment with regard to dying, enabling instead the circulation of narratives with a networked view of agency and that take seriously the importance of ending the dying person’s life story. I find that the narratives in my archive are told through the logic of choice, which focuses on the dying individual as autonomous agent in a context that is increasingly out of their control. This narrative construction often functions as a barrier to the good death. I speculate that a shift toward narrating end of life through the logic of care instead – which centers on ending the dying person’s story and on distributed care, agency and responsibility – would shift the concept of the good death and, thus, standards of judgment for

evaluating end of life. The question of how we might live a good life until the end and what discourses and structures might enable the most people to achieve that goal is worth exploring precisely because death is something everyone will experience. Shifting end of life rhetorics would allow us to tell different stories and may shift interactions with medical institutions, judgments about end of life, preparations for dying and our identities as (future) dying people and their loved ones.

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## Preface

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## 1.0 Introduction

Every society organizes around death in one way or another. The beginning of the 21<sup>st</sup> century has seen a surge of discourses critiquing how medical institutions and Americans, broadly speaking, discuss, prepare for and treat end of life. In this dissertation I perform a conceptually-oriented rhetorical analysis of the ideal of the good death, tracing this concept across a subset of contemporary discourses surrounding end of life. I analyze narratives of patient deaths recounted by healthcare practitioners in public discourse in order to understand the images of good and bad dying that are constructed within, some ideological investments of those images and the historical contexts that have given rise to these discourses. The primary goal of this dissertation is to provide a snapshot of some contemporary discourses surrounding end of life, accounting for the historical context, discursive constructions of the good death and some of the ideological implications of those constructions. Through close readings of contemporary narratives of the good death – including stories about both desirable and undesirable, both good and bad deaths – this project illuminates some of the attitudes, beliefs and values surrounding death and dying which are articulated in the course of arguing for and against particular ways of death.

Overall, while productive in some ways, the narratives within my archive don't go far enough to address the end of life issues we face. Taking seriously the idea that public narratives surrounding health and medicine can shape how medical situations are understood and acted upon, I argue that a narrative shift away from the focus on decision-making and the dying person as the primary agent at end of life may shift standards of judgment with regard to dying, enabling instead the circulation of narratives that center on the distribution of agency across networks and take seriously the importance of ending the dying person's life story. Consistent with other recent

analyses (see Kopelson, 2019), I find that, collectively, the narratives in my archive are told through the logic of choice, which focuses attention on the dying individual as decision-maker and primary agent in a context that is increasingly out of the patient's control. This narrative construction makes the tasks of managing a good death more difficult. I speculate that a shift toward narrating end of life through the logic of care – which centers on distributed responsibility, care and agency, and which takes the idea of ending the dying person's life story seriously – would shift the concept of the good death and, thus, standards of judgment with regard to dying. Such a shift would allow us to tell different stories and, in turn, to see and act upon end of life situations differently.

In this introduction, I first give more detail about the project itself – its timeliness, the construction of my archive and a review of methods – and then provide the theoretical background which informed my approaches to public discourse and narrative within rhetorics of health and medicine, as well as an initial orientation to the concept of the good death and overviews of literature on end of life in rhetoric and communication. I end with an overview of the chapters of the dissertation.

## **1.1 Project Overview**

The contemporary moment presents a unique opportunity to analyze the values, beliefs and attitudes surrounding death and dying. Death and dying have been somewhat common topics in academic literature in the United States since the 1950's. In particular, much has been said about the medicalization of death, which was propelled by rapid advances in medical technology during and following WWII, making it increasingly possible to delay death (see Butler, 2013; Clarke et

al., 2010; Gawande, 2014). This prolongation of life led, in part, to the advancement of the denial thesis in psychological and sociological literature: the claim that Western cultures, and the United States in particular, are death denying cultures or that death is a taboo (Zimmerman & Rodin, 2004, p. 212). Despite routinely being contested and refuted, especially in sociology literature (see Exley, 2004; Kellehear, 1984; Walter, 1991), the idea has persisted, becoming a common trope in academic, as well as public discourses. Academic articles about death and dying, many claiming that Western cultures are in denial, have proliferated since the 50s, with thousands published in the US by the early 1990s (Water, 1991). In addition, Segal (2000) and, more recently Kopelson (2019), point us toward the idea that public discourses surrounding death and dying have cycled in and out of prominence – with ‘waves’ occurring in the mid-60s, attributed primarily to Kübler-Ross’ (1969) *On Death and Dying*, in the ‘90s with Nuland’s best-selling *How We Die* and again in the 2010s.

That the early 2010s saw a renewed interest in end of life issues is evidenced by a proliferation of texts dealing with death, dying, grief and end of life issues. For example, news outlets routinely report on topics such as debates over aid in dying laws (e.g. Hartocollis, 2015), preparing for the management of email and social media accounts after a death (e.g. Sydell, 2015), the popularity of college courses on death (e.g. Hayasaki, 2014), and so on. In addition, books dealing with questions of what makes life worth living at the end, like Gawande’s (2014) *Being Mortal* and Kalanithi’s (2016) *When Breath Becomes Air*, became best sellers. End of life issues have also been the subject of recent movies, documentaries and conversation groups (see Institute of Medicine [IOM], 2015, pp. 352-54). Furthermore, people like Brittany Maynard, Lisa Bonechek Adams, and Oliver Sacks have challenged the idea that dying is supposed to be private, that one should shy away from the spotlight once they know they are dying (see Egan, 2014; IOM, 2015,

p. 366; Sacks, 2015). In different ways, each of them publicized their dying and worked to make their deaths visible, though there was pushback to this ‘dying out loud,’ indicating that ambivalence about talking publicly about dying remains (see IOM, 2015, pp.366-67). Despite this pushback, there seems to be an ongoing ‘national conversation’ surrounding death, dying and end of life issues.

There are many factors that contribute to this prominence of end of life issues in public discourse.<sup>1</sup> As mentioned, rapid technological and medical advances have led to longer lives through the ability to delay death. As these advancements have occurred relatively recently, today’s Baby Boomers are, really, the first generation to have witnessed dying prolonged through medical and technological intervention (Hardwig, 2006; IOM, 2015, p. 353). Furthermore, with increased life expectancies and as the Baby Boom generation ages, the overall population of the United States has aged and will continue to do so. As more and more people are reaching the stage of life where death is statistically most common, it follows that these issues would be coming to fore. Experts speculate that this will only increase (see Doka, 2003; IOM, 2015, p. 352). In addition, the ideal of patient autonomy is a highly-regarded value in medical contexts and, as a result, patients have increased say in – and are increasingly responsible for – their medical treatments and overall health. The former Institute of Medicine<sup>2</sup> (IOM, 2015) notes the extent to which the patient as consumer trend renders people “less passive about accepting care that violates their own wishes” (p. 353). All of this is, of course, amplified by changing media and increased access to media platforms, enabling people like Bonchek Adams, for example, to develop a following by blogging about her experiences of dying from breast cancer (p. 366). Increasingly,

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<sup>1</sup> This will be discussed in more detail in Chapter 1.

<sup>2</sup> Now called The Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine.

people are able and willing to share end of life experiences, especially negative ones, and have found and created audiences for the topic (p. 353). All of which is to say that the conditions are ripe for analyzing discussions of end of life issues.

This national conversation presents an opportune moment to study the cultural, social and rhetorical dimensions of death and dying. Death is the only certainty in life – or one of two, as the old adage goes – but what is not given is how we organize around, make sense of and approach end of life. The stories we tell ourselves and each other about end of life matter: they shape expectations of, preparations for and approaches to dying and death – our own, as well as those of others; additionally, these stories impact what stories are told later, whose deaths are narrated and whose are not, how those stories are told from which platforms, how those deaths are evaluated and so on. Thus, the question of how we might live a good life until the end and what discourses and structures might enable as many people as possible to achieve that is one worth exploring precisely because death is something everyone will experience. In the process of presenting arguments about how Americans do die and how we should, about how American society is organized around death and how it could be otherwise, these contemporary rhetors articulate beliefs, attitudes and values about death, dying and how we approach end of life. The contemporary discursive landscape presents a *kairotic* moment in which to consider the worldviews inherent in discussions of death and dying.

I was struck by how many contemporary texts surrounding end of life issues rely on narrative evidence for their claims that medical institutions, as well as broader American culture, needs to change how they approach and organize around death. These narratives include stories of patients, colleagues, friends, parents and other loved ones enduring drawn out and painful endings or, on the other hand, of people who witnessed deaths that were meaningful and moving; I

encountered stories of people who came to terms with the inevitability of their own deaths and of people who were unprepared for the deaths of their loved ones, in some instances even while they knew that their loved ones' condition was terminal or incurable. Journalist Amanda Bennett (2013, April) gave one such TED Talk following the death of her husband in which she laments a lack of stories about letting go, citing this lack as one reason for her own unpreparedness. Bennett, and other end of life researchers (e.g. Lynn, 1997), have called for the development of new stories to supplant the common narratives of the heroic patient and doctor battling death, and those of prolonging life at all costs (see Segal, 2000). They speculate that part of what is needed are new narratives about letting go, narratives for accepting death and focusing on the present, rather than on hope for extended futures. Given the prominence of narrative that I saw within contemporary end of life discourses, and in the context of ongoing calls for new narratives, I center my analysis on narratives of patient deaths.

### **1.1.1 Research Questions and Archive**

For this project I analyzed physician narratives of good and bad deaths in order to understand some images of the good death that are circulating within contemporary discourse. While not all of the texts in my archive explicitly mention the good death, it is an animating concept that helps us understand how end of life is framed and evaluated. My overarching goal in this project is to provide a snapshot of these discourses and how the concept of the good death is mobilized in the early 2010s by addressing the following questions:

- What is the historical context that has given rise to end of life discourses in the 2010s? To what are these discourses responding?

- What image(s) of the good death are constructed and advocated for within these discourses?
- Within these constructions, what contributes to a good death and what is a barrier?
- What ideological investments are inherent within these image(s) of the good death? What are the implications of these ideologies? What impacts might they have?

I attempt to understand these discourses by considering the interplay between texts and the contexts in which they were produced and circulated, by reading them through the concept of the good death.

In order to address these questions, I assembled an archive of 27 narratives of good and bad deaths written by physicians, published in print and digital media, and circulated through broad publics.<sup>3</sup> This archive is comprised of narratives by medical professionals (doctors, nurses, surgeons, and so on) in *The New York Times* (NYT) op-ed series about end of life, ‘The End’ (2015-2016), as well as by practicing surgeon Atul Gawande in his bestselling book *Being Mortal* (2014). For this project I don’t consider the NYT articles or book or chapters from Gawande as a whole, but rather pulled out the narratives used in support of the larger arguments being made – by which I mean, stories recounting presumed true-events told from a particular point of view and including a causal and temporal structure.<sup>4</sup> They include stories about the good or bad deaths of patients, colleagues, friends, and loved ones, which are primarily used as evidence supporting the authors’ arguments for changing the ways Americans approach and organize around death.

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<sup>3</sup> Of these 27 narratives, there are four that factor into my analyses but that I do not reference as examples in the dissertation: Helen Ouyang (2016) ‘The cultural contours of saving a life’ and David Casarett (2015) ‘Lessons in end-of-life care from the V.A.,’ both from ‘The End,’ and the stories of Lee Cox (pp. 158-161; 164-65) and an unnamed patient of Gawande’s (pp. 180-81) from *Being Mortal* (2014).

<sup>4</sup> The definition of narrative is discussed below in section 1.2.1.

‘The End,’ which ran from January 2015 through February 2016, covered a range of issues surrounding end of life, written by people who had lost loved ones, medical professionals, people diagnosed with life-limiting diseases and a few by non-medical death-related professionals (for example the president of Compassion and Choices, the U.S.’s oldest advocacy group for aid in dying laws, or a co-founder of The Conversation Project, an initiative to facilitate end of life conversations). I singled out the 16 articles from the series that were authored by medical practitioners – emergency room (ER) or intensive care unit (ICU) doctors and nurses, surgeons, hospice and palliative care doctors, specialists or nurses, and primary care physicians – and included at least one narrative.<sup>5</sup> In these articles, as well as in the broader series, there is quite a bit of attention paid to advanced care planning conversations and documentation, in part, at least, because Medicare reimbursement for advanced care planning conversations with doctors went into effect at the beginning of 2015. In addition, these op-ed articles cover topics such as the steps that occur in pronouncing a death in the hospital, the complexities of different cultural approaches to end of life, barriers to a good death and so on. The majority of the articles make use of patient narratives in order to make their overall points, either with several shorter examples given in support of different points or structuring the entire article around a single narrative or two. While I could not find information on the readership of this particular series, the overall circulation of the *NYT* is large, with the 18<sup>th</sup> largest circulation in the world. Furthermore, several of the articles

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<sup>5</sup> There are a total of 19 articles authored by healthcare practitioners that ran as part of ‘The End.’ I excluded the three following articles: VJ Periyakoil’s (2015) ‘We need a role reversal in the conversation on dying,’ which does not include any narrative elements; Mary Ersek’s (2015) ‘Transforming nursing home care,’ which includes one six-sentence story about discovering that one particular nursing home patient with dementia preferred powder instead of lotion at bedtime as the only narrative; and Scott Eggener’s (2015) ‘The murderer in the mirror,’ dealing with a surgeon’s complicated grief after losing a patient during surgery. The first excluded article does not refer to any narratives to make its case and the second two are different enough in kind from the rest of the archive that I excluded them from analysis.



published as part of ‘The End’ include published reader responses, so at least some of them sparked enough conversation and/or controversy for the paper to publish letters in response.

In addition to the *NYT* articles, I also analyze 11 of the narratives dealing with end of life recounted by Atul Gawande in his 2014 bestseller, *Being Mortal: Medicine and What Matters in the End*. The primary argument of Gawande’s book is that the project of medicalizing and delaying death has failed. Gawande is hopeful that individual people and medical institutions can find ways to improve end of life experiences, primarily through a focus on well-being, rather than on treatment, survival or health, throughout a person’s life but especially at the end (pp. 259-60). Gawande is a practicing surgeon and spoke with doctors, specialists in geriatrics, hospice and palliative care, nursing home directors, staff and residents, as well as patients of various ages and conditions and their loved ones, in order to explore contemporary end of life. Some of the narratives he recounts are experiences he witnessed or in which he participated, though he also repeats experiences recounted to him by others.<sup>6</sup> Throughout the book, Gawande makes use of these narratives to provide evidence for his claims, to give concrete examples of statistics and data, or to contextualize recommendations from the specialists he spoke to. *Being Mortal* appeared on a range of bestselling lists, including the *New York Times*, *The Economist*, *The Wall Street Journal* and NPR, was the subject of a number of reviews and was made into a Frontline documentary on PBS.

I selected texts by medical professionals because these authors chose to recast experiences with death and dying that occurred in medical contexts for broader public circulation. These stories, many of which are narrated as first-hand accounts, carry the implicit *ethos* of medical and

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<sup>6</sup> The first half of *Being Mortal* centers on what makes life worth living for elderly people, especially focusing on nursing homes and other elder care models. I do not discuss those narratives here, instead analyzing the 11 narratives about medical intervention and decision-making at end of life, which, generally, makes up the second half of the book.

health professionals and offer specific types of evidence of cultural, systemic and institutional failures when it comes to death and dying – namely, evidence that is based on multiple experiences with end of life issues and the medical and institutional knowledge through which to understand those experiences. Which is to say, while personal narratives of a loved one’s or even one’s own experiences with end of life issues are persuasive, by their nature as one, situated experience they don’t speak to larger cultural or institutional issues in the same way as narratives from someone who is embedded within an institution, has many experiences with end of life and chooses to speak out. Additionally, I was curious about the translation of medical experiences, likely cast in medical and institutional terms in other retellings, for lay audiences. Presumably it is because of their experiences with patients and loved ones at end of life that these authors are moved to push for changes in the way Americans die and, in order to do so, have translated their experiences into narratives to circulate within public discourses in an effort to enact social and institutional change.

These texts do not come anywhere near representing the totality of contemporary approaches to death in the US – and there are many differences along class, racial, ethnic, religious, regional and individual lines, which the narratives in this archive are largely silent upon. These texts circulated through one dominant public in the US: the middle class, typically white, person who consumes print and digital media and, generally, can be understood to be in a position to attempt to manage, control and prepare for their future, end of life included. Calls to prepare for death, to ‘have their affairs in order,’ to consider their values so that they might guide decision-making at end of life and so on, are calls to people who, statistically, will die in old age, likely from a terminal or chronic condition and who have access to the resources (money, time, healthcare, familial networks, etc.) that makes shaping end of life possible. Generally speaking, this means middle- and upper-class people with longer life expectancies (see Chetty, et al., 2016;

Murray, et al., 2006). Additionally, much of the academic literature on the good death and death studies more broadly focuses here as well, particularly on people with terminal illnesses such as cancer.

I choose to focus on these relatively mainstream publications because that they saw fit to cover end of life issues is indicative of some shift in discursive norms and part of my interest has been in how these (counter)discourses and articulations of the good death within have changed over time. If, as the broader discourse to which these texts contribute seem to claim, there is a push to tell new stories about end of life and to challenge the status quo in some way, I was initially curious what these stories were about, what they focused on and the concept of the good death within.

### **1.1.2 Methodological Approach**

While I draw on literature from a range of disciplines in this project, I am analyzing instances of health and medicine-related public discourse from a decidedly rhetorical lens. Following other scholars of rhetorics of health and medicine, rhetorical analyses allow us to examine the roles of discursive practices in shaping judgment, understanding, and future action, in making and/or enacting collective decisions in pursuit of the good life (see Keränen, 2014; Lyne, 2001). Thus, a rhetorical analysis of concepts related to end of life points us toward the ways that various forms of symbolic action influence our perceptions of, approaches to and judgments of death, dying and end of life issues.

Following this disciplinary focus, my research questions are aimed at understanding the historical context for contemporary end of life discourses, articulations of the concept of the good death within and what these articulations may mean for how we understand, approach and evaluate

end of life; which is to say, very simply, I am asking why now, what is this version of the good death and what are some of its implications? In order address these questions, I approached my archive through a conceptually-oriented analysis, centering on the concept of the good death.

Conceptually-oriented criticism calls attention to the interplay between text(s), their contexts and the concepts that animate or influence them. “The conceptual orientation examines the way that particular concepts that shape or inform symbolic activity are expressed in significant texts and using [*sic*] this exchange to explore shifts in human consciousness and standards of judgment” (Grey, 2009, pp. 342-343). In the attempt to understand a text (or set of texts) and how it may influence consciousness or standards of judgment, the conceptually-oriented rhetorical critic first identifies a concept at work in a text and, second, analyzes how that concept functions within the text. In providing an account of the concept in relation to the text and its potential impacts the critic, third, illuminates shifts – or potential shifts – that contribute to shaping standards of judgment and/or human consciousness. The concept at work in the text informs understandings of the text, as well as the possibilities for action or judgment in response to it and, in turn, the text itself shapes understandings of the concept. The concept thus shapes and is shaped by the standards of judgment of those participating in the circulation of the particular public discourse, including the critic themselves, and, further, shapes and is shaped by the text.

Conceptually-oriented criticism seeks to understand a particular concept as an idea or framework that informs how a text is read and acted on, as well as illuminating how that concept functions within the text, how that concept is impacted by the text itself, and how it impacts broader cultural dialogues through shifting standards of judgment and/or human consciousness. Analyses of this sort consider the broader ideological, historical, strategic or aesthetic frameworks that shape the texts’ appearance, affect our own perceptual processes and standards of judgment, and make

legible particular actions. This general orientation to a set of texts, the contexts which produce them and in which they are read, and the concept(s) that shape their reception calls for methodological flexibility, and thus, while considering the texts through the concept of the good death throughout, I employ a slightly different approach in each chapter, discussed further in the chapter overview section.

Through the overarching framework of conceptual orientation, I consider shifts in the concept of the good death, how the good death shapes and is shaped by end of life narratives and what types of actions and further narrativization are warranted based on this conceptualization. As noted, I argue that while the narratives are productive in some senses, collectively they perpetuate some of the very risks of bad deaths that they advocate against.

## **1.2 Theoretical Framing**

### **1.2.1 Rhetorics of Health and Medicine, Public Discourse and Narrative**

While I draw from other bodies of literature, this project, which seeks to uncover the worldview(s) inherent within stories of good and bad deaths circulating through particular publics, is founded on rhetorics of health and medicine, public discourse and narrative theory. Following Keränen (2012), rhetorics of health and medicine is a sub-field of rhetorical studies concerned with “how specific symbolic patterns structure meaning and action in health and medical contexts and practices” (p. 37) and, further, Meloncon and Frost (2015) identify it as one that seeks to uncover how “discourses create situations and allow participants and users to act on them” (p. 7). Thus, rhetorics of health and medicine direct attention to the various ways that conceptualizations and

performances of health and medicine-related concepts impact knowledge, action, identities, judgments and so on. The goals of my project align with those of the study rhetorics of health and medicine as I am seeking to understand how end of life – and the ideal of the good death in particular – is constructed within a particular set of public discourses authored by healthcare practitioners. Understanding these constructions provides, among other things, insight into how end of life is approached as a significant life event, including what types of knowledge are available or sought out, how people act in response, the standards of judgment that inform evaluations of dying and so on, for a particular public.

While rhetorics of health and medicine began with a narrower focus on medical institutions and medical models of care, work in this sub-field has broadened to include health-and medicine-related discourses that circulate as part of broader public discourses, as the narratives in my archive do (see Scott, Segal & Keränen, 2013; Keränen, 2014; Meloncon & Scott, 2018). Public discourses are those that are circulated, contested, enacted and/or rearticulated by publics and counterpublics (Wilson & Eberly, 2009). They both articulate and reinforce viewpoints with which people identify and, possibly, influence people to identify in particular ways (Condit, 1999). Following Warner (2002), discourses are ‘world-making;’ that is, they portray the world in particular ways and “attempt to realize that world through address” (p. 422). Thus, discourses carry with them worldviews, beliefs, values, and, following Foucault (1990), transmit, reproduce, undermine and/or expose power relations that the publics through which they circulate are, at least implicitly, asked to identify with (p. 101). There are a multiplicity of mutually-shaping publics and constitutive discourses, which respond to different elements of rhetorical situations – and to one another – in fluid, interacting systems, with differing levels of institutional or infrastructural support, as well as different levels of access to different platforms (see Edbauer, 2005;

Kuchinskaya, 2014). Regardless of the interplay of multiple contesting discourses, in any public members are active participants in the circulation, performance, articulation and/or re-articulation of the inherent worldviews. Speaking specifically of medical texts, Keränen (2014) summarizes, saying “In short, a rhetorical model of publics presents an inclusive vision of health and medicine as [a] networked, public exchange and encourages us to see participants in health and medical processes as more than consumers, clients and patients” (p. 105). The practitioner-authors in my study are thus attempting to ‘realize’ particular worlds through the narratives they tell and those who consume, respond to, contest and/or act upon these discourses are active participants in shaping these worlds. With this in mind, this project is aimed at uncovering what versions of death – and therefore of life – are being called for in these practitioner narratives.

Narrative is one site of research at the intersections of public discourse and rhetorics of health and medicine, especially focusing on the role of cultural narratives surrounding illness, health and human life and, in particular, the capacity of those narratives to empower and constrain storytellers. Insofar as rhetoric is concerned with symbolic meaning-making, it makes sense that narrative would be one site of rich theorization within rhetorical scholarship in general. While conceptions of what a narrative is vary somewhat (see Avraamidou & Osbourne, 2009), the minimum characteristics necessary to constitute a narrative include at least two events, linked causally through a temporal structure, told from the point of view of a narrator or author (see Foss, 2004). These constitutive characteristics are typically expressed in the form of characters, who we understand to be representative of actual people in non-fiction or personal narrative, to whom events happen, making up the general plot of a narrative which takes place in particular settings. As practitioner of narrative medicine Rita Charon (2001) writes, narratives rely on experiences,

rather than explicit proposition, in an attempt “to illuminate the universally true by revealing the particular” (1898).

Narratives are of particular importance as they are a foundational way of shaping understandings of the world by creating meaning out of events, orienting us toward some things over others and, importantly, constituting identities. Narrative is thus a means of creating and sharing knowledge, judging individuals and events, transmitting values and shaping actions within a particular community (see Charon, 2001; Fisher, 1999; Foss, 2004; Rowland, 2009). They are a resource to help manage the uncertainty of human life by creating ways of being, knowing and evaluating in common and, as with other forms of discourse, function as implicit arguments for viewing the world, ourselves and others in particular ways. Furthermore, we understand ourselves and share ourselves with others through the stories we tell about ourselves, which provide understanding of and structure for one’s sense of self (see Linde, 1993; Lingis, 2007). Arthur Frank (1995) asserts, our “selves are perpetually recreated in stories. Stories do not simply describe the self; they are the self’s medium of being” (53). Thus, our lives have beginnings, middles and, eventually, endings made up of particular moments collected into our narrative self. There are many events that can disrupt one’s self-narrative – chronic or terminal illness being one such, which may “require[s] the construction of a new life story” (Romanoff & Thompson, 2006, p. 309). Additionally, as the dying person does not get the opportunity to end their own story, at some point it is left to others to narrate the dying person’s life story, and that of their death. The narratives in my archive portray the particular experiences of healthcare practitioners with patient deaths and thus attempt to constitute a shared vision of end of life – including evaluations of dying, how we understand ourselves and others as dying people, what actions and reactions are called for and so on; visions both of how it is and how it could be otherwise.



There is relatively little research on physician narratives of patient illness/death, especially those narratives circulated in public discourse, however patient or survivor illness narratives have received quite a bit of scholarly attention. The end of the 20th century in particular saw a rise in the publication of illness narratives. Some theorize that this growth of the personal illness narrative is a pushback against the scientific focus of modern medicine and is an attempt at reclaiming the individual's experience of illness (see Segal, 2006, p. 60). However, there is concern that the inducement toward coherent narrative accounts of illness, and narratives that fit particular genres, can limit how we understand ourselves and our diseases (see Defossez, 2018; Segal, 2005; 2007). These limitations may further shape how others approach their own illnesses, as these types of narratives serve communal functions as well: "People tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others – each must create his own – but rather to witness the experience of reconstructing one's own map" (Frank, 1995, p. 17). Kleinman (1988) further argues that the retrospective illness narrative "reaffirms core cultural values under siege and reintegrates social relations whose structural tensions have been intensified" (p. 50). These narratives are not only about reconstructing one's sense of self or 'providing a map' to others but are also about reinforcing or changing the values of the community in some way. Segal (2005) agrees, arguing that all illness narratives – retrospective or not – perform this epideictic function (pp. 59-73).

Much of this literature on patient illness narratives can be applied to practitioner narratives as well, including those published for public or lay audiences. Physicians are increasingly reflecting on their own experiences practicing medicine through narrative, publishing not only in professional journals but also books and essays for public audiences (Charon, 2004, p. 862; Kopelson, 2019). As with autobiographical patient illness narratives, these narratives are told to

give some sort of coherence to the experience of practicing medicine and caring for ill and dying people, which is often emotionally taxing, at times even dehumanizing. Narratives help render their experiences whole, as Charon put it (2004 p. 862), thereby providing insight on the experience. Additionally, many practitioner narratives are explicitly told for some purpose, to transmit a lesson. The insights healthcare practitioners learn through narrativizing their experiences call to be witnessed by others, serving a similar epideictic function as illness narratives. The narratives shared with colleagues re-create and transmit the shared culture of medicine and practitioner narratives published for lay audiences reshape perceptions of medicine, contributing to a “social rhetoric of illness” (Frank, 1995, p. 21). One could take this further and make explicit that these narratives, drawing from the professional *ethos* of medical practitioners, not only shape how we talk about illness, health and interactions with medical institutions, but guide actions, shape judgments and help constitute our identities with respect to these things too.

Drawing on these understandings of the functions of practitioner narratives, in this project I analyze publicly-circulated practitioner narratives of patient illness to uncover the lessons practitioner-authored narratives of patient deaths share with the public through which they circulate. As with other health- and medicine-related discourses, rhetorical framing of death, dying and end of life issues is an attempt to create shared visions of death, the dying process and dying people. In praising some types of deaths, and imploring that we avoid others, the narratives in this archive draw on and actively shape the concept of the good death in the attempt to realize particular ways of organizing around the fact of our mortality, thus reinforcing particular values over others. The ideal of the good death has a long history, some of which will be covered in Chapter One, though an initial orientation to the concept, and how it is understood in sociological and medical

literature, is useful for understanding my approach to the individual texts and the project as a whole.

### 1.2.2 The Good Death

While there are many different facets of end of life discussed as part of the ongoing conversation on end of life issues, I focus on discussions about the ideal of the good death. Any prescriptions for or questions about how one *should* die – for example: how one would choose to die if they could, the nature of the deaths people and institutions should aim to facilitate, strategies for successful or at least ‘good enough’<sup>7</sup> dying and so on – are discussions about achieving a good death. The evaluation of a death, whether it is good, bad or somewhere in between, is co-constructed by the dying person, loved ones and healthcare professionals (Steinhauser et al., 2000). Thus, the ideal of the good death functions both as a goal to strive for while dying and as a way of framing someone’s dying process in hindsight. For example, calls to ‘prepare for the unexpected’ by having one’s affairs in order (e.g. will, advanced directive, naming a healthcare proxy, life insurance, etc.) is a strategy to help one achieve a good death by being prepared in advanced to mitigate the negative impacts of dying. Or, to take another example, a mother requesting that her children visit as her health deteriorates so that they might all, hopefully, achieve some measure of closure in the chance to say goodbye, is an attempt to shape the dying process such that psychological and social consequences are managed. On the other hand, narratives of a soldier’s ‘heroic sacrifice in the name of their country’ or of a 30-something who ‘lost their battle with

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<sup>7</sup> As the good death is an idealized version of dying, the concept of a ‘good enough’ death, which allows for a dying person to come as close their idealized version of dying as possible given their circumstances, has also been forwarded (see McNamara, 1998). Additionally, while there does not seem to be a strict definition of the term, some use the term ‘successful dying’ as essentially interchangeably with ‘good death’ (e.g. Meier, et al., 2016).

cancer’ are both examples framing the dying process after the fact in order to help to make sense of the death, through the virtues of sacrifice for the good of society or the refusal to give up even against insurmountable odds, for example.

All of which is to say, the ideal of the good death shapes preparations for end of life in advance, during the dying process and reflections on a death after the fact. Further, the ideal of the good death, as both a goal to strive for and as a way of framing a death after the fact, serves an epideictic function, reinforcing a society’s highest values, by reinforcing the systems, myths, narratives and/or ideologies through which it is perpetuated (see Kastenbaum, 2012, p. 465).

We are in a transitional moment in approaches to end of life. Up until World War II, people were statistically most likely to die in the ‘prime’ of life and, as a result, the goal of medicine was to prolong life as long as possible (Hardwig, 2006). As mentioned, narratives still circulate today that support this goal: the heroic doctor battling death, the courageous patient who sacrifices everything for the chance of pushing death back a few more years, if not into old age. However, with the widespread availability of advanced medical technology and practices in the years after WWII, it has become possible to significantly delay death and, as we see now, the majority of people in the U.S. will die in old age (Arias & Xu, 2019). Furthermore, medicine is increasingly able to identify and diagnose the diseases from which, statistically, most people will die, extending the dying process into long dying – dying which can take weeks, months or even years (see Walter, 2003). Given that medicine runs up against the biological limits of the human more often than up against medicine’s ability to prolong life, the question of when to permit death, rather than seeking to prolong life, is raised, necessitating new narratives, as well as, possibly, a new ideal of the good death.

There is little agreement as to what, specifically, constitutes a good death for an individual person (Meier et al., 2016, p. 262; Steinhauser et al., 2000, p. 830). However, contemporary academic literature generally conforms to a palliative care conception of the good death, which emphasizes awareness of dying, autonomy and a self-chosen coping style, open and honest communication about death, and acceptance of dying, or at least the idea that “death is something to be learned from,” as general elements (Goldsteen et al 2006 p. 379). According to several reviews of academic literature patient treatment and dying preferences – as well as patient preferences on the timing of death, when to delay death and when to permit it – are central elements of the good death (see Goldsteen et al., 2006; Meier et al., 2016; Steinhauser et al., 2000). In addition, emotional, psychological, spiritual and/or social support for the dying person, as well as their loved ones, open communication between patient, family and healthcare personnel, awareness of dying, and acceptance or transcendence of death all figure in as elements of a good death in one form or another, though, again, what these elements entail in practice will differ based on the dying individual. Adequate management of pain and symptoms are key features, as well, and are considered to be a foundational element, enabling the dying person to take up the dying role by completing the practical, relational and personal tasks associated with dying – such as completing end of life planning, saying goodbyes, passing the torch on to successors, giving permission for spouses to remarry, completing last rites or otherwise achieving some measure of closure (see Emanuel, Bennet & Richardson, 2007).<sup>8</sup> Inherent within this conceptualization of the

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<sup>8</sup> The idea of the ‘dying role’ is, essentially, another frame for understanding the ideal of the good death, largely through social constructivism. Oliver-Parker (1999-2000) is often credited with developing the concept, however Noyes & Clancy (1977) originally proposed dying as a social role distinct from the sick role in a critique of hospital care at end of life. See Emanuel, Bennett and Richardson (2007) for a thorough summary of key features of the dying role, breaking them into practical, relational and personal tasks.

good death is that individuals continue to ‘be themselves’ for as long as possible and that the ending should fit the individual (see Goldsteen, et al., 2006, p. 381; Kastenbaum, 2012, p. 467).

This individualized approach to end of life mirrors trends in healthcare, and discourses surrounding health, more broadly. Scholars in the medical humanities, rhetorics of health and medicine and other related areas have argued that individuals are increasingly responsible for seeking out health-related information, maintaining their health, preventing health issues, deciding courses of treatment and so on. This responsibility is often framed as empowering patients to take an active role in their healthcare and/or increasing patient (or consumer) choice when it comes to healthcare, but many rightly note the extent to which these discourses further biopolitical regimes of self-control and self-regulation (e.g. Lupton, 1995; Metzl, 2010; Spoel et al., 2014). These discourses center on the concept of autonomy, which gives a patient the authority to control their own treatments but also carries with it a particular subjectivity. As Keränen (2007) writes, “Once a necessary corrective for the abuses of Tuskegee, Nazi experimentation, and rampant physician paternalism, autonomy is predicated on the assumption of an autonomous individual agent who desires to make informed (read rational) decisions about individual health” (p 189). The autonomous patient is in control and, thus, is considered to have agency, which is usually the framed as the capacity to know, prevent and/or decide in health-related situations (see Defossez 2016). This individualized and active version of the ‘patient’ is something of a contradiction of terms, as the patient has historically been conceived of as a passive recipient of medical treatment administered by the paternalistic, authoritative doctor. While some have shifted to speak of patients as ‘consumers’ of medical services or as ‘lay people’ in the lay-professional relationship (see Dew & Jutel, 2014), I use the term ‘patient’ in this project primarily because that is the term used by

the practitioner-authors of the texts I analyzed and, further, to reinforce that these stories are narrativized from within a medical view of end of life.

In this context of contemporary individualized medicine, the ideal of the good death includes control over the dying process itself, ideally guided by the individual patient, in order to facilitate the patient's capacity to take up the dying role and complete practical, relational and personal tasks independently or delegating them as needed. This control can only extend so far though – as Byock (2015) reminds us in an *NYT* op-ed, “modern medicine has yet to make even one person immortal” – and so the primary question at end of life eventually becomes when to cede that control, to cease treatment and permit the person to die. As noted, many of the common myths and narratives of end of life support the idea of pursuing the prolongation of life at all costs. Among other things, this focus has contributed to the trope of the US as a death denying society (see Becker, 1973; Zimmerman & Rodin, 2004), though this is contested in sociological literature (see Kellehear, 1984; Walter, 1991).

Regardless of where one falls on the question of the denial thesis, in some senses death is always a public matter. The three primary tasks following a death are first to dispose of the body, then to make the implications of the death real to community members and to reintegrate the community that has just lost a member (Corr, Nabe & Corr, 2009, p. 292). The rituals surrounding mourning after a death – as well as many of the preparations while a person is dying – work to achieve these goals and are carried out by survivors in accordance with the traditions and laws of the community. As such, death is always bound up in public and communal life, though how the tasks associated with death are conceived of and distributed has shifted over time, with the work of dying increasingly individualized and recognition of dying increasingly public in globalized societies (Kellehear, 2007). Which is to say, on the one hand, preparations for dying have shifted

from a community task to an increasingly individual or personal sphere of responsibility and awareness that someone is dying has shifted toward institutional or public control in the form of hospital/biomedical, nursing home and/or state definitions of death, an argument echoed in Keränen's (2007) article about patient preferences for end of life worksheets. Overall, sociologist of death and dying, Kellehear (2007) argues that public control over recognition of dying has resulted in decreased awareness of death.

Additionally, many sociologists and death studies researchers have debated the discursive norms through which death, dying and related end of life issues are discussed. Noting several competing discursive frames – including practical, biomedical, public health and governmental, semi-psychiatric and therapeutic, as well as religious frames – Walter (1991) speculates that the loss of a coherent language with which to discuss issues surrounding death and dying contributes to the perception of its taboo (pp. 303-4). Related, rhetorics of health and medicine scholar, Judy Segal (2000), discusses two competing sets of discourses for approaching end of life, one which constructs dying as a human experience that circulates in public discourses and the other, based in biomedical discourses, especially those occurring within hospital settings, construct death as a medical failure. The contemporary narratives I analyze for this project are perhaps evidence of an attempt to overcome this divide, to realign the discourses of the public and the technical spheres by portraying deaths in hospital settings, narrated by healthcare practitioners as, more or less, human experiences.

Despite the epideictic nature of the ideal of the good death, the inherently public nature of the work associated with dying and this focus on public discourse, there is not a lot of literature on end of life issues within rhetoric or rhetorics of health and medicine. As Kopelson (2019) notes, most rhetorical work on end of life considers deliberation over aid in dying discourses and



legislation (e.g. Hyde, 2001; Hyde & McSpirit, 2007; McDorman, 2005), or on decision-making at end of life (e.g. Segal, 2000; 2005; Keränen, 2007). Kopelson's article, published at the end of 2019 and looking at some of the same discourses as this project, is the only study I know of that centers on the ideal of the good death.

Thus, this project seeks to enter and extend conversations about the potential of public narrative – especially practitioner narratives of patient illness/death – to shape how medical situations are approached and judged. In this project I provide a snapshot of a transitional moment in end of life discourses and practices.<sup>9</sup> The importance of end of life issues in medical- and health-related discourses has been slowly established within rhetorics of health and medicine, but, as indicated, there is an overall dearth in rhetorical literature on the ideal of the good death. Furthermore, there is little theorizing in general on the logic through which the concept of the good death is articulated and acted upon.

Centering on narrative not only points us toward a particularly influential form of public discourse, as overviewed above, but also one in which it is potentially easier to intervene in pursuit of addressing issues surrounding end of life. In attempting to uncover some of the attitudes, beliefs and values imbedded in a potentially influential set of rhetors' constructions end of life and the ideal of the good death, I am not only commenting on how past, present and future end of life – and potentially other medical – situations are understood, but also how a fundamental aspect of our lives is discursively constructed and organized around. The good death is one lens through which death and dying are understood. Careful attention to how end of life narratives draw their conclusions allows us to intervene in that conceptualization. A shift in the rhetoric of dying may shift responses to health and medical-related situations, interactions with medical institutions,

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<sup>9</sup> See Cross & Warraich, 2019, Dec. 12; also, discussed further in the conclusion to this dissertation.

judgments about and preparations for end of life, as well as how we live in the face of death and understand our identities as (future) dying people and their loved ones. In part this project is an attempt to shed light on what we, broadly speaking, value as evidenced through public narratives about end of life. Dying is the one event that touches every single living thing and, as such, broadly shapes the structure of our lives and society, whether we are aware of it, accept it or not (see Bauman, 1992; Becker, 1973). Understanding more about the end of life narratives that circulate through public discourse helps shed light on how our individual lives and social structures are organized, conceived of and evaluated.

### **1.3 Chapter Overviews**

In the first chapter, I provide historical and discursive context the concept of the good death and the texts that make up my archive, arguing that contemporary narratives of good and bad dying are part of larger advocacy for death acceptance. This advocacy, I further argue, is an extension of the mid-twentieth century death awareness movement. I break contemporary advocacy into two, interrelated strands: on the one hand, the death positive movement, which seeks to counter cultural denial of death, and, on the other hand, what I am calling advocacy for ‘well-timed’ dying, which primarily focuses on addressing the prevalence of futile treatments or unwanted life prolongation. The practitioner narratives that make up my archive fall in this second strand in that, generally, they are concerned with medical approaches to dying and attempt to facilitate better deaths by encouraging better choices at end of life. In this chapter, I overview contemporary death acceptance discourses as a whole, as well as the earlier death awareness movement in order to provide context for understanding end of life narratives and articulations of good versus bad dying

circulating in the 2010s. I rely on both primary and secondary sources to account for the interplay between text and contexts considering the ways that articulations of the good death have (and have not) changed over time.

The second chapter introduces the narratives that form the basis of the dissertation and addresses the question of the images of the good death constructed within, as well as the practices (and so on) that facilitate or function as barriers to a good death. This chapter places the concept of the good death within the texts themselves, finding that the good death functions as an ideal to strive for and shapes the evaluation of the narratives. I organize the narratives into a critical typology, arguing that they focus on type of treatment, the role of the patient and/or on broader social and structural issues, with stories of good and bad deaths told within each focus. Collectively, I read these narratives as forwarding an ideal of the good death that results from low medical intervention and in which uncertainty on the part of patients and/or loved ones is minimized, the patient retains agency as long as possible and the social needs of patients and loved ones are met. While stated somewhat reductively here, one of the primary ‘lessons’ of these stories is that a good death is contingent on patients and/or proxies making the right decisions: medical knowledge and established approaches to end of life are generally presented as given and it is up to patients and loved ones to decide what to do in response. However, I do identify two narratives that don’t fit this generalization and, in different ways, make calls for medicine to adjust to specific patients and to change approaches to dying in medical contexts. Thus, in Chapter Two I account for the interplay between text and concept through a close textual analysis of the texts themselves. I identify the evaluatory ideal constructed within these texts and offer one argument for how they reinforce or seek to shape judgments of the roles of medicine at end of life.

The final chapter considers some of the implications of those constructions of the good death – that is, what actions, judgments, narratives and so on are warranted by the particular conceptualization of the good death – by rereading the narratives of my archive through the lens of what Annemarie Mol (2008) calls the logic of choice versus the logic of care in medical practices. These narratives are predominantly narrativized through the logic of choice, which perpetuates the ideology of the autonomous individual decision-maker and typically renders healthcare practitioners narratively passive. While some dying people and their loved ones are able to articulate narratives of good dying through the logic of choice, I argue that the narrativized logic of choice more often acts as a barrier to good dying, as it cannot account for the historical life of the dying person and often cuts patients off from their caring networks. When viewed through the lens of care, the concept of good dying shifts, directing attention to the distribution of agency across a dying person’s caring networks and the necessity of ending the dying person’s story. In this chapter, I seek to address the question of the ideological investments of these constructions of good and bad dying, as well as their potential implications, by an ideological analysis of the narratives. Ultimately, I speculate that a generalized shift from choice to care in end of life narratives may also shift standards of judgment with regard to end of life, helping to facilitate better approaches to dying by telling different stories.

Altogether, I argue that narratives centering on the agency of the autonomous, dying individual – and especially those that center on end of life decision-making as the primary moment that agency is enacted – won’t address the issues of futile treatment or prolonged deaths, won’t protect patients from practitioner or institutional overstep, nor expand access to the possibility of the good death to those who are disadvantaged socially, economically or otherwise. Indeed, as

recent trends in end of life show (see Cross & Warraich, 2019, Dec. 11; 2019, Dec. 12),<sup>10</sup> making the, ostensibly, right decisions at the right time does not *necessarily* lead to better dying. A shift away from the logic of choice, possibly toward the logic of care, would also shift the focus in end of life discourses, enabling us to more effectively address the issues rightfully raised within contemporary end of life discourses.

Overall, as stated, my primary goal is to provide a snapshot of these discourses in order to understand what impacts they might have on how we, broadly speaking, organize around death. Personally, I am interested in the creation of structures and discourses that facilitate better dying and coping with death. Which is to say, those structures and discourses that enable more people to prepare for their own death, or those of loved ones, and facilitate dying in the least distressing manner possible, for the dying person, as well as any surviving loved ones and, if possible, healthcare practitioners. While I am excited about the existence of the broader discourse I analyze here, I am simultaneously critical of its potential to change organization around death or to facilitate good dying on a broad scale.

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<sup>10</sup> This is discussed in more detail in the Conclusion.

## 2.0 Chapter One: End of Life Advocacy in the U.S.

Contemporary end of life discourses are often explicitly framed as arguments against standard practices in caring for dying people. The majority of these discourses characterize the ill effects of these practices as a result of three interrelated things, each of which poses issues for pursuit of the good death: a thoroughly medicalized view of death and dying, overcomplicated healthcare systems and a perceived taboo on discussing death and dying. Here, I argue that contemporary conceptualizations of the good death forwarded in books, op-eds, essays, blog posts and so on, originate with the end of life movements that emerged in the mid-20th century. These contemporary discourses advocate for death acceptance by seeking to counter the perceived denial of death in contemporary culture and/or the prevalence of futile or unwanted prolongation of life common in medical institutions.

In this chapter, I offer a brief overview of these end of life movements in the United States, attending in particular to the discourses surrounding social, technological and medical developments of the 20th and early 21st centuries as a context for understanding contemporary narratives of good and bad deaths, and the concept of the good death more broadly. Specifically, I argue that end of life discourses of the early 2010s are an extension of the mid-20th century death awareness movement.<sup>11</sup> Originating in the '60s, this movement argued that Western societies, and the U.S. in particular, were death-denying societies that overly medicalized and professionalized dying. Thus, proponents argued, the need to promote awareness of death, dying and other end of

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<sup>11</sup> Reflecting literature in the sociology of death and dying, I refer to the loose network of scholars and activists working toward death awareness as a 'movement' (see for example Doka, 2003).

life issues and, further, to articulate the possibility of a good death. I argue here that contemporary counterdiscourses build upon the foundations of the earlier movement for death *awareness* in arguments for death *acceptance*, which, I further argue, has two basic camps.

I see contemporary advocacy for death acceptance falling into two primary strands, one focusing on death and the other on dying. The first is called the ‘death positive movement’<sup>12</sup> by proponents (see Order of the Good Death) and, through death-centered media, gatherings and discussions, has the goal of normalizing death, breaking the perceived taboo surrounding death and even celebrating the fact of our mortality in everyday life. The second, which I call advocacy for ‘well-timed’ dying,<sup>13</sup> aims to impact the medical choices of dying persons.<sup>13</sup> It is this second strand that is the primary focus of this dissertation. Both strands of death acceptance build on, respond to and extend the legacy of mid-century death awareness movements and clearly overlap in their purposes, one of which is to promote the ideal of the good death. However, proponents of death positivity are primarily working to address a perceived taboo surrounding discussions of death, while advocacy for well-timed dying attempts to counter the prevalence of futile or unwanted treatment by encouraging better decision-making at end of life.

In order to set the stage for these discourses surrounding death acceptance, I first give an overview of the mid-century death awareness movement and second consider in more depth the movement’s articulations of the history of death as professionalized, medicalized and denied, as well as their promotion of death as natural and suggestions for the possibility of a good death. It is this set of articulations that set the foundation for contemporary discourses surrounding end of life. The second half of the chapter provides an overview of contemporary advocacy for death

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<sup>12</sup> Death positivity is called a ‘movement’ by participants. I will reflect their language throughout this chapter.

<sup>13</sup> I explain the phrase ‘well-timed dying’ in more detail in section 2.3.2.

acceptance. Responding to and building off the work of the earlier death awareness movement, the contemporary death positive movement has developed a cultural narrative about end of life in pursuit of acceptance of death and advocates for well-timed dying are developing individual narratives of dying in practice.

## **2.1 Part One: The Death Awareness Movement**

The death awareness movement of the 1960s and '70s was a loose network of scholars, activists, counselors and practitioners who sought alternatives to the prevailing attitudes toward death, dying and bereavement. They were primarily responding to developments in medical technology that became prominent after World War II, which, they argued, shifted responsibility for the work of dying from the individual and their community to the sphere of medical professionals (Doka, 2003). They objected to the common practice of hiding terminal diagnosis from patients and the medical abandonment of people who could not be 'fixed.' Overall, the movement for death awareness critiqued the deathways of the time as overly medicalized, institutionalized and generally characterized by denial. They looked back nostalgically to previous eras, in which, it was argued, dying people were in control of their own deaths and the work of dying was largely undertaken by family and community members.

The late 1950s through the 70s saw a flurry of writing and activism on end of life issues, primarily in the U.S. and the U.K. This included a range of scholarly works that inaugurated the sociology of death and dying subfield, as well as the interdisciplinary subfields of death studies and thanatology, and led to the creation of academic societies and journals (Doka, 2003). In addition, there were several influential works that resulted in institutional, political and cultural



change: Dame Cicely Saunders' work in medicine and as a social worker led her to establish the modern hospice in London in 1959, which spread to the U.S. with the opening of Connecticut Hospice Branford, Connecticut in 1974; journalist Jessica Mitford's investigations into the U.S. funeral industry, published in the popular book *The American Way of Death* (1963), led to governmental intervention and industry changes in funeral practices; and Elizabeth Kübler-Ross' influential research on dying people, which became *On Death and Dying* (1969), established a widely popular paradigm for approaching dying and bereavement. These and other works propelled end of life issues into public discourse. Many included narratives of illness, dying, bereavement and/or funerary practices, which might have been considered morbid even just ten years earlier but were readily consumed in the late '60s and '70s (Bregman, 2017, p. 469).

Elizabeth Kübler-Ross' *On Death and Dying* (1969) became one of the groundbreaking works of the movement as a whole and is likely one of the most enduring legacies of the death awareness movement. While working as a psychiatrist at the University of Chicago's Billings Hospital, four theological students approached Kübler-Ross asking for help with a research paper on death. They decided to interview dying people in order to understand a first-hand perspective on end of life. However, while searching for patients to interview, the task was complicated as none of the healthcare workers or staff would identify any of the patients as 'dying' (Kübler-Ross, 1969, p. 19-21; Bregman, 2017, p. 468). Once interviews finally began, patients expressed that they were living in isolation, scared of abandonment, angry, depressed and unwilling to accept their imminent deaths. However, they were also thankful for the opportunity to share their experiences and, for some, to talk about approaching end of life. In contrasting these experiences with her recollection of end of life in the Swiss village of her childhood, Kübler-Ross argued that there were better ways of dying.

These interviews provided the foundation for *On Death and Dying* in which Kübler-Ross posits five stages of dying: denial, anger, bargaining, depression and acceptance. This stage theory was later extended beyond dying and applied any type of loss, bereavement in particular. Overall, Kübler-Ross' message was one that "rejected dehumanizing medical technology" (Doka, 2003, p. 6) and championed the idea that there was room for growth and development even in dying. The idea that someone could actually accept their own or someone else's death was a radical idea at the time (Bregman, 2017, p. 468).

*On Death and Dying* was widely read and indeed established a new paradigm for approaching dying, loss and bereavement, one that is still frequently applied today. However, many academics criticized the work as including 'unverified' research that romanticized dying (see Doka, 2003, pp. 12-13). Furthermore, some questioned the methodologies Kübler-Ross employed (Hart et al., 1998, pp. 68-69), argued that there was little evidence for the stages – for example, no patient was depicted as having reached the stage of acceptance (Bregman, 2017, p. 468) – and that while the work was an account of dying within a hospital setting, the findings were presented as a-contextual (Hart et al., 1998, pp. 68-69). Despite these and other critiques, there is no doubt that Kübler-Ross' work was particularly influential and has impacted how people approach death and loss in public, private and technical spheres. Indeed, one of the primary critiques of the stage theory is that it has been too readily accepted and people – including healthcare providers – apply it too rigidly, possibly resulting in feelings of failure if someone fails to progress through the stages 'properly' (Hart et al., 1998, p. 69; Bregman 2017, p. 468).

Just before Kübler-Ross published her pioneering work, Cicely Saunders was developing the first modern hospice in London. After working as a wartime nurse, social worker, and training as a doctor, Saunders focused her clinical attention on patients in the terminal phase of illness –

who at the time were often overlooked or abandoned by physicians – and was particularly concerned with the management of pain at this stage of life. She founded St. Christopher’s Hospice in 1967 with the goal of integrating her research on pain management with the “tender loving care” approach that hospices of the time were already practicing (Saunders, 1978, p. 726). Saunders theorized the unity of physical and mental suffering, developing the concept of total pain which includes suffering at the physical, mental, emotional and social levels (Clark, 2007, p. 431). Pain and symptom management were thus the foundation of Saunders approach to end of life care:

The care of the dying demands all that we can do to enable patients to *live* until they die. It includes the care of the family, the mind, and the spirit as well as the care of the body. All these are so interwoven that it is hard to consider them separately. (Saunders, 1965 p. 71)

Saunders’ was one of the first to argue that dying people require special care and, similar to some of Kübler-Ross’ work, she argued that end of life was not “defeat, but rather... life’s fulfillment” (p.70), an innate and natural part of life. Thus, the ideal of the good death is central to the modern hospice movement.

The idea and ideals of modern hospice were one of the most influential aspects of the movement for death awareness. After St. Christopher’s opened in 1967, hospice spread across the Atlantic to the U.S. in 1974. There were upwards of 1,200 hospices across the U.S. within the next four years (Doka, 2003, p. 10). The ideas that dying people require and deserve special care, that a good death is possible and, along with Kübler-Ross, that dying can be a time for development and growth have shaped contemporary approaches to end of life.

The death awareness movement included more scholarly, popular and professional works than just these, but, even from this brief overview, we can identify some key ideas on which the movement was founded. First, that the medicalized and professionalized approach to dying led to

a denial of death, hence the need to raise awareness of end of life issues. And second, the call to reclaim death from this institutionalized approach, returning to a view of dying as a natural part of life, one requiring particular care and attention. This approach to end of life has generally been accepted within public discourses and, further, similar arguments circulate as part of contemporary end of life narratives.

The advocacy of the death awareness movement has had some lasting impacts on approaches to death, dying, bereavement and end of life. In particular, following the work of Kübler-Ross, Saunders and others, literature on end of life and dying people shifted to primarily focus on systematic observation and research, as opposed to relying on isolated, individual anecdotes. There was also a shift toward active care of dying people and a view of end of life as a period calling for special attention and care, as noted. Much of this care came to focus on the dignity of the dying person and on finding meaning at end of life. These shifts were enabled by the broader movements for patient autonomy and bioethics, and as informing patients of their terminal status became standard practice. Additionally, Saunders' concept of total pain was part of a revolution in understanding the relationships between physical and all forms of mental suffering (Clark, 2002, p. 905).

Finally, as noted, the spread of hospice has arguably been the biggest medical impact of the death awareness movement. According to the CDC, as of 2016, there are currently more than 4000 hospice care agencies in the US, serving 1.4 million patients (2016).<sup>14</sup> Contemporary ideals of the good death generally conform to a hospice and, closely-related, palliative care<sup>15</sup> approaches

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<sup>14</sup> Data on the number of hospices is as of 2016 and the number of patients is from data collected in 2015.

<sup>15</sup> The concept of palliative care was developed by Balfour Mount, who trained at St. Christopher's Hospice with Dame Saunders. The primary distinction between palliative and hospice care is when care begins. Palliative care may begin at the time of diagnosis and continue concurrently through curative treatment, while hospice care begins once curative treatments have stopped.

to end of life, centering on the dignity and autonomy of the dying person, awareness and acceptance of impending death, adjustment to and preparedness for dying and peacefulness (Goldsteen et al., 2006 p. 378; Howarth, 2007, p. 137). By the 1990s, the death awareness movement had become largely institutionalized (Doka, 2003, p. 11).

While institutionalization represents one type of win for any social movement, there are also concerns that come along with it. In particular, as hospice has expanded and been incorporated in mainstream healthcare institutions, there have been concerns about hospice and palliative care actively contributing to the further medicalization of dying and about the goals of hospice being subverted by these medical institutions (Clark, 2002; Field 1994; McNamara et al., 1994). The ideological differences between hospice and mainstream curative treatment pose challenges for the incorporation of hospice into healthcare institutions and, while hospice care still serves as a “symbolic critique” of terminal care in other settings, it is still dependent upon the structure and rituals of traditional, institutionalized medicine (McNamara, 1998, p. 171). Similar to some critiques of Kübler-Ross’ stage theory, the concept of the good death which has been inspired by this shift toward the *ethos* of hospice care has established normative expectations surrounding dying – especially the idea that death should somehow be meaningful for patients and loved ones – that may lead to the idea that people can fail to die properly (see Goldsteen et al., 2006; McNamara et al., 1994).

As Lucy Bregman (2017) has argued in her review of the death awareness movement, medically speaking the movement had limited impact. Physicians still lack adequate training in communicating about end of life, despite the reforms of the patient autonomy movement and informed consent end of life decision-making is still fraught and difficult, institutional and insurance structures still push people toward acute care, and there are still issues over defining

when death has occurred and identifying dying people (Bregman, 2017, p. 472; see also IOM, 2015).

That being said, the biggest impacts of the movement have arguably come in an increased willingness to witness and to discuss end of life, as well as the vocabulary and framework through which those discussions take place (Bregman, 2017, p. 472). Which is to say, the idea of the denial of death versus those of acceptance, dignity and viewing death as a natural part of life, and the idea of a medicalized fight against death versus the possibility of a good death that can be meaningful for all involved, have framed ongoing national conversations about end of life issues.

Given this discursive impact, we now turn to examine the professionalization, medicalization and resulting denial of death as articulated in histories of death and dying, largely forward by the movement for death awareness. In Part Two below, I draw from Ariès' (1974a; 1981) formative work on attitudes toward death over time, which was influential in the movement, as well as that of contemporary sociologist of death and dying, Kellehear (2007). This overview gives a sense of prevailing views of the social, medical and technological contexts which shaped the death awareness movement's articulations of end of life issues and their conceptualization of the good death. Following this, we will consider the move to articulate death as a natural part of life and the ideal of a good death as a response to these contexts.

## **2.2 Part Two: A History of Death and Dying**

Since about the mid-twentieth century, the history of end of life has largely been articulated and re-articulated as a grand narrative. Phillipe Ariès' work on the history of death and dying in Europe was a landmark moment, inaugurating the study of the history of death and inspiring much

of the later death awareness movement. Based primarily on analyses of literature and art, Ariès was one of the first to chart shifts in attitudes toward death in western Europe and the United States and his books – *Western Attitudes Toward Death* (1974a) and *The Hour of Our Death* (1981) – were very influential. Despite this, Ariès’ work has been widely criticized, most notably for offering overly romanticized versions of death and dying in the Middle Ages. Additionally, the historical rigor of his work has been called into question, as his work makes use of evidence from all over Europe without attending to cultural or religious differences across space and time (Walter, 1991, p. 297). These and other critiques notwithstanding, Ariès work is at the center of both modern conceptualizations of the good death and the history of death and dying (Hart et al., 1998, p. 66). Later social historians and sociologists have corrected and updated Ariès’ work, including sociologist Allan Kellehear, who’s *A Social History of Death and Dying* (2007) I also draw on in this section – though many essentially offer their own grand narratives in place of the one Ariès authored.

In what follows I give a summary of the history of death and dying, drawing especially from Ariès (1974a, 1974b, 1981) and Kellehear (2007). As indicated by the critiques summarized above, Ariès’ history is a sweeping narrative that, taking western Europe as a whole, breaks history from ancient times to his contemporary moment into four epochs of attitudes toward death: the ‘tame death’ stretching from ancient times through the 11th and 12th centuries, the ‘death of the self’ up to the early 18th century, the ‘death of the other’ encompassing the 18th and early 19th centuries and the ‘forbidden’ or ‘invisible’ deaths of the late 19th and 20th centuries. These characterizations of attitudes toward end of life, especially the tame death of Middle Ages and the death of the self in the Renaissance and Enlightenment periods, offered a comparative for the death awareness movement and were influential in their articulations of alternatives. Ariès’ final period

of the forbidden or invisible death generally characterizes how advocates for death awareness perceived their contemporary moment.

Kellehear's (2007) social history also breaks the history of end of life into four categories. However, rather than organizing them chronologically, as Ariès does, Kellehear centers his categories on broader economic and social organizations, which result in particular challenges for end of life, and is careful to point out that each of these social organizations exist today. For Kellehear, the first category is the nomadic society in which the issue of anticipating death is the most pressing; the second are pastoral or agrarian societies in which preparing for death is the biggest challenge. Third, Kellehear considers end of life in the city, in which he says 'taming' or managing death becomes paramount and, finally, the task of timing death is the biggest challenge in cosmopolitan or globalized societies. Contrasting to Ariès, Kellehear draws from a wide range of disciplines, marshalling archaeological, epidemiological, historical and sociological data, among other sources, to make his case.

In my brief overview of this history below, I make use of information from both sources, as well as a few others, in order to construct a view of the historical impacts of professionalization and medicalization on end of life, which, according to the death awareness movement, resulted in a deep-seated denial of death in the United States. To do so, I begin with Kellehear's 'age of the city' and Ariès history of the 18th, 19th and 20th centuries. In the second subsection, in which we consider the ideas that the death awareness movement articulated in response to that denial, – namely that of death as a natural part of life and the ideal of the good death – I will cover Ariès' earlier epochs of the tame death (up through the 11th or 12th century) and the death of the self (which stretched to the early 18th century), as well as Kellehear's discussion of end of life in pastoral or agrarian societies. In Part Three of this chapter, I review what some contemporary



sociologists of death and dying have said about the current era of death and dying, including Kellehear's work on the cosmopolitan society, before turning to the contemporary public discourses of the late 20<sup>th</sup> and early 21<sup>st</sup> centuries, which draw on this history.

### **2.2.1 The Professionalization, Medicalization and Denial of Death**

According to Kellehear, the shift toward urbanization affects social organization around end of life in three ways. First, the social work of dying was outsourced to professionals. Increased urbanization gives rise to a specialized labor force and the accumulation of wealth, leading eventually to the development of a middle class. Classes of merchants, artisans and skilled laborers grow and consolidate in cities, leading to the development of professional classes whose power derived from increasingly specialized knowledge and skill in their profession. The professionalization of death in western Europe arose in this context as the middle and upper classes began to hire doctors, lawyers and priests to attend to the medical, legal and religious elements of dying that had previously fallen to the dying person and their family or community members in agrarian communities (p. 131; p. 134). This shift toward professionalization necessitates that management of death by hiring the right people, rather than necessarily preparing for one's own death as is the case in agrarian societies. In this way, then, dying became increasingly privatized through the Middle Ages and Renaissance in Europe – combined with weakening familial and community ties that come along with life in the city – and part of an economic transaction.

Second, the epidemiological context of the city eventually gives rise to the long dying<sup>16</sup> that is characteristic of modern and contemporary times. Dying in urban areas is increasingly stratified along class lines, with people in lower classes susceptible to infectious diseases from which the elite and much of the middle classes were shielded. The life spans of members of the upper classes increased during and after the Industrial Revolution and professionalization leads to increasingly sedentary lives (pp. 140-42). The extended, painful deaths of the wealthy – for example from cancer or heart disease – resulted in increased demand for medical care and the idea that a good death is only possible if the dying person is comfortable, relatively pain free and lucid enough to make the necessary arrangements (pp. 143-44). The need to manage pain and physical symptoms, only possible because of concurrent medical advances, compounds the overall management approach to dying to which professionalization gave rise. This increase in medical management of dying eventually spread to the lower classes as well, as public health measures slowly increased lifespans and spread long dying among populations as a whole.

Third, both Ariès and Kellehear speak of a growing resistance to dying that comes along with the social, economic and medical contexts of urban life. There are arguments linking professionalization with heightened anxiety, as people are increasingly dependent upon others for survival and advancement (see Kellehear, 2007, p. 135). This middle-class anxiety in the face of deskilling and reliance on others extends to the work of dying, too. The middle-class cult of expertise combined with a desire to produce a solution results in the need to actively solicit the right people to perform the right services (as well as the necessity of being able to afford it). Middle-class people come to be driven to *do* something in the face of death – hire the right people,

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<sup>16</sup> As mentioned in the Introduction, long dying, as opposed to sudden, usually traumatic, deaths, is the statistical norm today. Long dying occurs with foreknowledge of death, usually following a medical diagnosis, often of a chronic or terminal illness, and is typified by a longer, uneven decline.

seek a second opinion, call in another priest, and so on – that manifests in an active battle with death.

These three shifts in approach to end of life – professionalization, changes in what people commonly die from and a resistance to dying – occurred alongside the development of medicine in the urbanization of Europe. During the Enlightenment, death shifted slowly but steadily into the province of science and medicine. Both death itself and the dead body were refashioned as objects of scientific investigation (Ariès, 1981, pp. 353-54). The rise in popularity of dissection and anatomy, as well as increase in embalming practices and recurring fears over premature burial are indicative of both a fascination with and fear of death, Ariès argued (p. 398). Death was considered through the lens of science and medicine which distances it from everyday life, taking dying even further out of the everyday experiences of lay people and recasting it in scientific and professional frames.

For much of the 18<sup>th</sup> century, doctor and patient would negotiate diagnosis and treatment. While the doctor had formal training, the patient was seen as the source of knowledge about their own symptoms. In addition, both doctor and patient would have had at least basic knowledge of common remedies (Fissell, 1991, p. 92). Thus, early medicine was just one option among others that may heal a person, as Gawande (2014) put it “no different from healing ritual or family remedy, no more effective” (pp. 69-70). With the development of the microscope and, subsequently, germ theory and medical microbiology, over the course of the 19<sup>th</sup> century medicine became increasingly scientific and less philosophical. Doctors assumed control in diagnosis and treatment, while the lived experience of the disease – the patient narrative – was less important. The body and disease, now detached from the life and understanding of the individual, became the focuses of the gaze of modern medicine (Fissell, 1991, p. 100; see also Foucault, 1973).

The rise of medicine laid the foundations for medicalization in the 20<sup>th</sup> century, accelerating with medical and technological developments post-World War II. After World War II there were rapid advances in medical technology and treatments: increased availability of antibiotics, the use of electrical shocks to manipulate the heart, – leading to the first fully internal pace-maker in 1958 – the discovery of drugs to control blood pressure, artificial respirators, kidney transplants and so on (Butler, 2013, p. 66, 76; Gawande, 2014, p. 69). This rapid development led to the first intensive care unit (ICU) in 1961 to accommodate all the newest machinery and monitors (Butler, 2013, pp. 77-78). This innovation, along with the newly developed resuscitative practice CPR, and, eventually, emergency response systems, like the U.S.'s 911 system established in 1971, saved the lives of many otherwise healthy people who, for example, suffered heart attacks, overdosed or were involved in traumatic accidents. The reduction in sudden, accidental deaths increased life expectancy, led to more deaths in old age and dramatically reduced the frequency of death. The length of dying increased as well.

As a result of this trend toward medicalization, Ariès (1974) characterized dying in the 20<sup>th</sup> century as that of extreme denial, naming the epoch 'the forbidden death.' The epitome of this denial was seen in the once common practice of hiding a terminal prognosis from the dying person. According to Ariès, this is the culmination of the replacement of death with disease, which Kübler-Ross ran up against in her attempts to interview dying people. The dying person was no longer labeled as 'dying,' and/or not told they are dying, instead they were encouraged to focus on defeating the disease, on treatment options and getting better; someone with cancer may recover, while someone who is dying, barring the most exceptional cases, will not. Thus, rather than the patient 'is dying,' the patient 'has cancer,' effectively replacing dying with disease. Additionally, with the reduction in sudden deaths people were less familiar with death simply because they lived

through less of it. Lastly, Ariès also points to a decrease in the length of time spent mourning, as well as a weakening in mourning rituals, as evidence of the ‘forbidden-ness’ of death in this epoch. Shortly after the publication of his first book on the topic, though, Ariès noticed further shifts and re-characterized the time period as one in which death was ‘invisible,’ rather than forbidden in subsequent publications (1974b; 1981).

The ‘invisible death’ was characterized overall by discretion in the dying process and in discourses surrounding death and dying. While the practice of hiding terminal prognosis from patients was already eroding within a few years of publication of Ariès’ first book, dying people were still expected to be very discreet in their dying, he argued. Which is to say, the dying person was expected to continue to function in their social roles and, especially within the hospital setting, it was important that the dying person not be overly emotional so as not to upset visitors or hospital staff. Ariès’ analysis concludes that while death was not necessarily forbidden, one is allowed to die “only if he does not use it to upset the living” (1974b, p. 545). Similarly, Ariès notes that throughout time literature has dealt with the topic of death, the ‘ordinary man’ of the mid-20<sup>th</sup> century was silent about death, though the fact of that silence was beginning to garner academic interest and a proliferation of discourses within sociology and psychology – many of them influenced by Ariès himself. This discretion and hiding of death, which is typically talked about in terms of denial, resulted from the professionalization and subsequent medicalization of dying and was said to have especially characterize the American context.

### **2.2.2 Death as a Natural Part of Life and the Ideal of the Good Death**

As a response to this professionalization, medicalization and prevailing denial of death, members of the death awareness movement largely looked to the past for guidance on how to

reshape approaches to end of life. Ariès' work on the history of attitudes toward death was foundational to a set of nostalgic arguments (Hart, et al., 1998, p. 66; Wood & Williamson, 2003, p. 10). In contrast to the era of the 'wild death' – the forbidden and invisible deaths of the mid-20<sup>th</sup> century, discussed in the previous section – Ariès described the deathways of agrarian societies, and the European Middle Ages in particular, as the era of the 'tame death.'

In Ariès' historical narrative, for most of European history, death was largely familiar and, as such, not a fearful event. This familiarity with death constituted a pervasive 'general attitude' toward death throughout human history: death was an ever-present possibility for which one should be prepared and, furthermore, the individual was the primary agent directing preparations for their own death (1981, pp. 5-28). Ariès argued that death was familiar and not frightening, thus 'tamed' relative to modern attitudes. Contemporary sociologist Clive Seale (1998) counters that the claim of a reduced fear of is difficult to substantiate, but agrees the argument for death as familiar was most likely true, citing that people 'knew what to do' when death occurred (p. 51). For example, Ariès (1981) cites numerous literary illustrations in which the dying person knows the proper way to live out their last moments: how to position their body in preparation for death, what to say to the people who witnessed their death and so on (p. 14-17).

It was in this era that death became an individualized moment. In the early Middle Ages tombstones and monuments to the deceased were personalized for the first time, containing details about the life of the deceased in an apparent attempt to convey a sense of their identity (1974a, p. 52; 1981, p. 293). Christian images of the Last Judgment changed from depictions of the day God would judge humanity as a whole, to depictions of God judging of the life of the individual. According to Ariès death was still familiar and thus 'tamed' but, in addition, death became what completes the life of the individual and the moment in which one discovers their true identity

(1974a, p. 52; 1981, p. 293). This development, along with the spread of accepted preparations for death, contributes to the developing ideals of good versus bad deaths, which reflected the character of the dying person depending on how closely a specific passing aligns with the dominant customs.

According to Kellehear (2007), the long, slow transition from nomadic to sedentary life, which gave rise to more predictable, gradual deaths – as opposed to the sudden, traumatic dying more common in hunter-gatherer societies – created the opportunity for dying people to prepare for their own deaths.<sup>17</sup> Thus, ‘dying’ became a social identity in itself, a role one plays, allowing for the possibility to exercise some amount of control over dying. Not control in a medical or epidemiological sense, as doctors were few and far between and, for pastoral peoples in Europe in the Middle Ages, modern medicine didn’t exist. Rather, control in the sense of mitigating consequences to the community following the death of a member. Thus, a good death in these smaller-scale agrarian societies was one that affirmed the social and economic orders – in which social obligations did not go unfulfilled, in which the land, wealth and/or agricultural equipment necessary to ensure the survival and, hopefully, the prosperity of the community and future generations was passed on. Arguing against Ariès, Kellehear asserts that these social and material preparations were so important to the family and community that it is unlikely they were left entirely to the control of the dying person (p. 99). However, there is agreement that the dying person was at the center of these preparations and kin and kith were the ones who carried them out.

It is to this type of dying that the death awareness movement looked in order to develop their articulations of the ideal of the good death. As noted, Ariès’ conceptualization of the history

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<sup>17</sup> According to Kellehear (2007), in nomadic societies most of the social work of dying is undertaken by family and community members after biological death.

of death and dying was at the center of understandings of the good death (Hart et al., 1998, p. 66), and many of the later arguments against the medicalization of death rely on this history, most notably Illich's (1976) *Medical Nemesis*.

One of the primary arguments advocates of the movement for death awareness made is that death is a natural part of life, rather than an enemy to be battled or denied. In describing the death of a family friend in the Swiss village in which she was raised, Kübler-Ross' (1969) describes the "old-fashioned' customs" she witnessed: spending his last days at home, leaving final words to friends and loved ones, distributing his belongings and land, leaving tasks for his children to complete, and being laid out in his home following death for loved ones to pay their respects (p. 5). This scene is presented as evidence of the possibility for peace and dignity through the awareness and acceptance of death. Furthermore, Kübler-Ross comments that she, a child when this took place, was not excluded from any of these preparations and contrasts that with the practice of sheltering children from death by not allowing them to see dying family members or discuss their deaths, which was common at the time. When children are allowed to participate in preparations for a loved ones' death, she argues, they come to see death as a natural part of life (p. 6). This version of dying is contrasted with the "lonely, mechanical and dehumanized" (p. 7) deaths she witnessed in modern hospitals.

The ideal of the good death that arises from this view of death as a natural part of life is one of open communication, preparedness, acceptance, dignity and peace. While Kübler-Ross states that she does not want to do away with sedatives, pain medication or infusions, the idea of natural death is a reaction to what proponents saw as dehumanizing technology and medical practices. As Illich (1976) is often quoted as saying, "the medicalization of society has brought the epoch of the natural death to an end" (p. 77). Hospice emerged and spread partly as a response to



the ‘loss’ of natural dying, in part because it offered an updated version of a natural death: “in bed, at home and under benign medical care in which interventions to ensure painlessness are balanced with the autonomous choices of the dying individual and their close companions” (Seymour, 1999, p. 693). These ideals of a natural and good death, which were inspired by the particular version of the history of death and dying overviewed here, have been incorporated into contemporary ideals of the good death and have laid the foundation for subsequent discourses surrounding end of life. It is to the contemporary advocacy for death acceptance that we now turn.

### **2.3 Part Three: Death Acceptance**

It is from this legacy that advocates for death acceptance are making their claims in the early 21st century. While there have clearly been gains in the ways end of life is approached and conceived of since the mid-20th century, discourses of death acceptance continue to paint dominant attitudes toward death as characterized by denial, and even taboo, and dying practices as overly medicalized and dehumanizing. While contemporary end of life counterdiscourses share many of the arguments found in the death awareness movement, they are responding to the context of 21st century approaches to end of life, including demographic shifts and continuing developments in medical technology that have shaped the norms and practices of medical institutions, all of which shapes conceptualizations of the good death.

As the Baby Boomer generation ages, the number of Americans over 65 stands to increase dramatically. It is expected that 21.7% of the population will be over 65 by the year 2040, with a projected 94.7 million by 2060 (2018 Profile of Older Americans, 2018). In addition, we are now roughly one generation removed from the medicalized dying death awareness advocates were

arguing against, and as more people have witnessed their parents, friends and other loved ones die in this way, many are searching for a different end for themselves. Enabled by increased access to platforms from which to speak, there is a renewed interest in end of life issues and the ideal of the good death in particular.

Based directly on the legacy of hospice, contemporary literature on the ideal of the good death reflects the goals of pain and symptom management – the ideal being a pain-free death – and adhering to the preferences and decisions of the dying person as much and as long as possible (Meier et al., 2016; Steinhauser et al., 2000). In a recent review of medical and psychological articles relating to good (or successful) dying, 100% of patients and family members and 94% of healthcare providers included patient preferences for dying (e.g. funeral arrangements, advanced directives, preferences for when, where and with whom the patient wants to die, etc.) in their criteria for a good death (Meier et al., 2016, p. 267-68). After patient preferences for the dying process, pain-free dying (81%) and emotional well-being (64%) were the next most common themes reported by all three stake-holder groups, followed by life completion, treatment preferences, dignity, religion/spirituality and issues surrounding loved ones – such as family support, acceptance or preparedness – which were each identified by more than 50% of respondents (p. 265).<sup>18</sup> From this, a good death means the dying person makes their own decisions, and is thus in control of their dying, and adjusts to being a dying person – whether through goodbyes, life completion, meaning-making and so on – with symptom and pain management as a prerequisite that enables those things.

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<sup>18</sup> Interestingly, Meier et al. (2016) report that while quality of life was identified as an important element of the good death by only 35% of patients, 70% bereaved and pre-bereaved family members named it as a component.

However, the care people receive at the end of life often does not match the care that people say they want (Goodman et al., 2013). For example, most people state that they would prefer to die at home but the majority of deaths in the United States still occur in the hospital or other institutional setting, with only about 33% of deaths at home (Teno et al., 2013, p. 473).<sup>19</sup> Additionally, most cancer patients say they would prefer comfort or supportive care that minimizes hospital time at the end of their lives, yet almost 25% of cancer patients die in the hospital, with 62% hospitalized and 28.8% admitted to the ICU in the last month of life. It is also worth noting that, within this same data set, 61% of patients were enrolled in hospice care in the last month of life. However, roughly 11% of those people entered hospice only in the last three days of their life. Nationally, the average number of days in hospice care for Medicare recipients during the last month of life is only nine (Goodman et al., 2013, p. 2). Thus, despite evidence suggesting that people want comfort care in their homes in their last days and despite evidence that comfort care or hospice care improves the dying process, the most common approach to end of life care remains acute care, in hospital or other institutional settings.

The former Institute of Medicine's (IOM)<sup>20</sup> 2015 report, 'Dying in America,' builds on other IOM reports published in 1997 and 2003 to describe small gains in end of life care but also identifies several barriers to high-quality care at end of life. The report identifies barriers in accessing care, a mismatch between needed care and what the patient or family can obtain, lack of access to palliative care specialists, as well as lack of knowledge of palliative care among physicians, a lack of coordination across institutions and specialties within institutions, and the

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<sup>19</sup> It is worth noting that for some, institutional settings are home, so these data may be misleading.

<sup>20</sup> Now called The Health and Medicine Division of the National Academies of Sciences, Engineering, and Medicine.

current insurance system which encourages the use of acute, rather than comfort, care and contributes to the high number of transfers between institutions at the end of life.

Today, the majority of people in the U.S. die of chronic or terminal illnesses later in life. The top six leading causes of death in the U.S. are heart disease, cancer, unintentional injuries (poisoning, motor vehicle accidents, falls, etc.), chronic lower respiratory diseases (e.g. COPD, asthma, occupational lung disease, pulmonary hypertension), stroke and Alzheimer's disease (CDC, 2017). The total life expectancy for people born in the U.S. was 78.6 in 2017 – a slight decline from 2016 (78.7 years) and the third year in a row overall life expectancy has declined in the U.S. (Jostz, 2018).<sup>21</sup> Aggressive interventions later and later in life have become the norm and, as a result, we see high levels of care administered at end of life (Kaufman et al., 2004, p. 732). According to Gawande (2014), in the U.S. 25% of Medicare spending goes to the 5% of patients who are in their last year of life (p. 153). “In the last five years of their lives, a quarter of the elderly now spend all of their savings, including the value of their homes, on caregiving and other out-of-pocket medical expenses. 43% lose everything except their homes” (Butler, 2013, p. 14).

In addition to these direct financial costs, there are also an estimated 39.8 million Americans acting as caregivers for an adult (AARP/National Alliance for Caregiving, 2015, p. 9). While noting that there is increased support for and recognition of the role that family caregivers play, ‘Dying in America’ (IOM, 2015) finds that demand for family caregivers is increasing and that the roles they play are expanding. Increasingly, family caregivers are taking on medical and nursing tasks – managing medication, medical equipment, wound care or nutrition, for example – in addition to personal care and household tasks. So, as care for the dying is expanding to include more laypeople, these laypeople are increasingly delivering medical care, that is care coordinated

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<sup>21</sup> Note: The life expectancy rose slightly in 2018 (see Xu, et al., 2020).

and authorized by medical institutions. All of which is to say there are a lot of people shouldering the financial, emotional and physical burdens of longer life expectancies.

Within this general context, contemporary sociologists of death and dying have moved to incorporate late 20<sup>th</sup> and early 21<sup>st</sup> century norms in end of life into their end of life taxonomies. For example, Tony Walter argues that death has moved into the province of the individual. With political and economic globalization and the “fragmentation of modern values,” the modern death, against which death awareness advocates were arguing, has largely been replaced by what Walter calls the postmodern death (see Howarth, 2007, p. 18). Death in the postmodern condition is highly individualized; the individual is the authority in charge of making decisions about their own dying process, replacing doctors and medical institutions that were the decision-makers in the modern death. The individual is expected to cope with the experience of living with death through the expression of their feelings and the work of death takes place in the social context of the family, rather than the hospital or the broader community as in Walter’s modern and traditional deaths, respectively.

On the other hand, Kellehear (2007), labels death in the contemporary globalized context as the shameful death – in which people die ‘too soon,’ in poverty, without the ability to properly prepare, often from preventable or stigmatized diseases (e.g. AIDs) or, on the other hand, ‘too late’ after languishing in nursing homes in a form of social death, having outlived loved ones and possibly their own bodies or minds. Furthermore, Kellehear sees an erosion of awareness of dying as characteristic of globalized societies, though he means this in a more specific sense than those advocating for death awareness in the ‘60s and ‘70s. The dying trajectories associated with

statistically common causes of death makes identifying the onset of ‘dying’ difficult<sup>22</sup> and the issue is further exacerbated by the separation of life/living and death/dying into two distinct states of being (p. 210). According to Kellehear, then, the biggest challenge in our contemporary, globalized society is that of timing death: of ensuring that social death aligns with biological death, of when to permit a patient or loved one to die versus when to continue attempting to treat. This issue animates a lot of contemporary end of life discourses.

While there are of course differences among particular populations, especially falling along racial, ethnic and religious lines, there is data on where Americans as a whole fall on the questions of whether or not and under what circumstances it is acceptable for doctors to permit or hasten a patient’s death. A 2013 survey from the Pew Research Center showed that the number of people who agree that “medical staff should do everything possible to save the life of a patient in all circumstances” doubled since a similar survey in 1990 (IOM, 2014, p. 347); however, this increase is at least partly due to a decrease in the percentage of people who responded “don’t know” to the question in the more recent survey. In addition, though, the number of people who agree “there are at least some circumstances where a patient should be allowed to die” fell seven percent. These same polls also show little to no change in the numbers of respondents who would ask to stop their own treatments if they were in pain, dependent on others or had difficulty functioning, on the one hand, and a rise in the number of people who responded that they would want everything done to keep them alive as long as possible, on the other. Again, the 2013 version of the survey saw people shift away from “don’t know” in the 1990 poll, toward prolonging life in the 2013 poll (pp. 347-48).

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<sup>22</sup> As Gawande (2014) asks, “Is someone with terminal cancer, dementia, or incurable heart failure dying, exactly?” (p. 157).

The majority of people agree that discussing treatment wishes and other advance care planning is important but most have not done so (p. 125). There are many reasons people do not participate in advance care planning – uncertainty over process and forms, healthcare professionals unprepared to discuss end of life issues, not wanting to upset loved ones, and so on. Furthermore, despite the ongoing attention to end of life issues in public and academic discourses over the past 60 years, for some death is still a taboo topic in U.S. culture.

Within this context there has been an ongoing ‘national conversation’ surrounding end of life issues. News outlets routinely report on topics such as debates over the right to die (Hartocollis 2015), managing email and social media accounts after a death (Sydell 2015), the popularity of college courses on death (Hayasaki, 2014) and so on. Atul Gawande’s (2014) *Being Mortal*, which offers an analysis and, ultimately, commendation of our healthcare system’s approach to end of life care, spent many weeks on bestseller lists. Brittney Maynard’s very public move to Oregon in 2014 to end her life through the state’s Death with Dignity Act spurred increased interest in debates over aid in dying legislation – leading several states to vote on aid in dying legislation in the 2016 election. Citing Gawande and Maynard, as well as the IOM Report published in the same year and Ezekiel Emanuel’s (2014) widely circulated article about not wishing to extend his life past 75, The Washington Post declared 2014 “The year we finally learned how to talk seriously about dying” (Millman, 2014). *The New York Times* began its end of life series, ‘The End’ in early 2015. Medicare’s proposal to reimburse doctors for end of life conversations – which garnered intense concern over ‘death panels’ in 2009 – was quietly passed in 2015 and implemented in 2016. Even Jeb Bush spoke in support of advanced care planning, an apparent reversal of his position in the Teri Schaivo case (Haberman, 2015). Furthermore, the work of mortician Caitlin Doughty – in her ‘Ask a Mortician’ YouTube channel, death positive collective Order of the Good

Death and its sister group, Death Salon<sup>23</sup> – led many to declare that death has been “having a moment” (Hayasaki, 2013; Ortiz, 2016).

This moment seems to have continued throughout the 2010s, with continued attention to advanced care planning (Jain, 2019), funeral practices (Quirk, 2017) and corpse disposal (Lee, 2011; Recompose, 2018). We turn now to the two strands I have identified in these discourses, the death positive movement and advocacy for well-timed dying.

### **2.3.1 Death Positivity**

Caitlin Doughty, the mortician behind the ‘Ask a Mortician’ YouTube channel, coined ‘death positivity’ in a tweet in 2013: “Why are there a zillion websites and references for being sex positive and nothing for being death positive?” (@TheGoodDeath, 2013). ‘Ask a Mortician’ was two years old at the time; Doughty had already formed the “death acceptance collective,” Order of the Good Death (caitlindoughty.com, n.d.), and the gathering of ‘deathlings’ at the first Death Salon would take place a few months later. With Doughty’s tweet, the budding, mostly women-lead movement had a name. The death positive movement aims to reduce anxiety surrounding death, seeking a neutral acceptance of death by increasing interaction with death – by creating spaces for people to think and talk about end of life (see Booth, 2019). The stated mission of the Order is to make “death a part of your life. That means committing to staring down your death fears.... Accepting that death itself is natural, but the death anxiety and terror of modern culture are not” (orderofthegooddeath.com, 2019). The website is a collection of resources and information all about end of life issues and links with the works of other funeral industry

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<sup>23</sup> Co-founded with Megan Rosenbloom.



professionals, academics and artists invested in changing attitudes toward and practices surrounding end of life.

At about the same time Doughty was getting started, Jon Underwood of London came across the work of Bernard Crettaz and his café mortels. Using Crettaz's model, Underwood hosted the first Death Cafe – planned, informal gatherings of people to discuss issues related to death and to eat cake – in 2011. The movement has hosted over 9,000 conversations in 66 countries since 2011 (deathcafe.com, n.d.). The first Death Cafe in the U.S. was in Westerville, Ohio in 2012, with events happening in over 100 US cities since (Miles & Corr, 2015). Like Doughty, Death Cafes have received a lot of press, with articles appearing in the *New York Times*, NPR and other major news outlets, and, more recently, being the subject of some academic work. The objective of the group is “to increase awareness of death with a view to helping people make the most of their (finite) lives” (deathcafe.com, n.d.). There is no set agenda for the gatherings, the primary stipulations being that they are not bereavement groups and that there must be some type of food. Attendees have stated that they feel more comfortable discussing death after attending (Span, 2013) or “more alive” (Battersby, 2012) following discussions of this sort.

Doughty, Underwood and their projects use the language of increasing awareness of death and the necessity of reclaiming death from professionalization in an effort to combat denial or to increase comfort with end of life issues. They reiterate many familiar reasons for the lack of familiarity and comfort with death: severing from traditional death-related rituals, dying shifting from the home to the hospital and funeral preparations from the in-home parlor to the funeral parlor. This movement is notably less medical-focused than much of the earlier death awareness movement, however. Additionally, the contemporary context is one that sets this movement apart

from its precursor. As this article in *Marie Claire*, of all places, states, young people are very aware of death:

Maybe it's all the apps and fitness trackers that tell us exactly how alive we are at any given moment. Or the constant stream of new studies revealing that everything we love will give us cancer. Or the collective mourning on social media that immediately follows a celebrity death. Or the incessant mass shootings and Reddit threads that follow them. Or the chilling headlines about young women being raped and murdered while out on a jog, while leaving the office, while on vacation. (Ortiz, 2016)

As there was in the 1960s with the lingering threat of the bomb and fears of impending environmental collapse, there is in some ways a hyper awareness of death in the contemporary moment but at a distance. Death positivity is not necessarily about the (medical) care of dying people but of reading, thinking and talking about mortality as a way of making life better. Doughty, Underwood and others have called for acceptance of death into our lives as a way of making it less fearful, embracing it as an inevitable aspect of our lives.

There are many other facets of this cultural movement: conversation starter projects (Death Over Dinner), art projects (Before I Die), apps that remind users of their mortality (We Croak), centers for innovation in and the study of end of life issues (Columbia Universities DeathLab, Art of Dying Institute), and so on. In general, these groups reiterate the cultural narrative of western society, and the US, in particular, as in denial of death or, at the very least, in need of a 'redesign' for handling death and dying. They create spaces for discussion, art and innovation as a way of breaking down those barriers in order to make life better by thinking about and/or improving death.

In addition to these more formal groups, there is another recent trend noted in the IOM (2015) report. Pejoratively called 'dying out loud' by Emma Keller (2014) in an article in *The*

*Guardian*, this trend refers to dying people who choose, in various ways, to make their deaths public. Keller's article was about Lisa Bonechek Adams who discussed her diagnosis, treatment and preparations for death from cancer on her well-followed social media sites and blog. We could also count Oliver Sacks' *NYT* articles (2015) chronicling his terminal diagnosis and decline; Brittany Maynard's public decision to move to Oregon to take advantage of the state's aid in dying law following her diagnosis with brain cancer; Paul Kalanithi's (2016) book *When Breath Becomes Air* about his diagnosis and death; and so on. Adams and Maynard received a lot of backlash, indicating a remaining ambivalence about making dying visible in this way (IOM, 2015, p. 366). I see dying out loud as something of a borderline phenomenon between the death positive cultural narrative of a death-phobic society that needs to confront and change its relationships with mortality and the medical-based push for changes in how individuals approach and are guided through dying in advocacy for the well-timed death. Which is to say, dying out loud is the public circulation of one individual's dying process in order to achieve some measure of closure or acceptance surrounding their own end – as well as, possibly, some measure of immortality – and in order to impact the narratives surrounding approaches to dying, intra- or interpersonally, legally or medically.

### **2.3.2 Well-Timed Dying**

Agnieszka Janaik (2019) reviews many of the same groups I have discussed above and, in reflecting on the death of one of her own close friends, argues that we are entering a new epoch of attitudes toward death, one in which death is shared with others:

Support in dying and mourning is now at the centre of attention. The current attitude towards dying is what I call shared death – we no longer leave our relatives' dying to

experts – but we try to stay with them by ourselves: we try to accompany the dying on their terms, listening to their individual needs. The more and more common attitude is living with the dying. (p. 267)

In this view of dying, it is the individual who guides the dying process – as with Walter’s (1991) version of the individual death in postmodernity, overviewed above. But the work of dying – the carrying out of tasks and helping to ensure, inasmuch as possible, that everything goes as the dying individual wants – is distributed among friends, family and loved ones, and thus shared. Janaik especially contrasts this with the modern approach to dying, against which the death awareness movement spoke out, in which doctors and medical institutions took the lead and everyone else, oftentimes the patient included, was sidelined.

However, for every story of a good death, in which the community comes together to witness and support the passing of a member in whatever ways the dying person wishes – in which dying is shared in the way Janaik described – there are also stories of bad deaths, of prolonged endings in pain and suffering, of people who are “left to the experts,” as she terms it, and on the “conveyor belt” of care (Zitter, 2015, April). Many of advocates of what I, following Kellehear, am calling well-timed dying share narratives of good and bad deaths as a way of attempting to persuade people to begin thinking about their own end of life wishes and to share those with loved ones and/or doctors. The narratives are also part of advocacy for institutional and cultural changes to better support individual decision-making regarding end of life. The rest of this dissertation focuses on a subset of these discourses, so I will only provide a brief overview here.

Advocates for what I am calling ‘well-timed dying’ generally advocate for patient choice in dying, with the idea that, given adequate information and opportunity to plan, people will choose to forgo curative treatment at the time that is most fitting for their particular medical, cognitive,

emotional and social situations. Advocates for aid in dying take this a step further and argue that people should be able to actively end their own lives at the right moment – that is, the moment of their choosing. Thus, the ideal of well-timed dying, in these discourses, is primarily concerned with people who die ‘too late,’ as Kellehear puts it, and stems from the development of medical technology that has enabled the prolongation of biological life beyond the point of social death and physical or mental capacities, as well as on the movement for patient autonomy.

Discourses advocating for well-timed dying are thus concerned with a few interrelated issues. Responding to a medical and technological situation that allows for the radical extension of biological life and against institutional and cultural privileging of the prolongation of life and the continuation of treatment regardless of the odds, advocates for well-timed dying assert that there is a ‘proper’ time to die. The individual patient’s choice is first and foremost in determining when that is. Therefore, most of the focus of these discourses is on improving individual decision-making at end of life, through advanced care planning, increased access to palliative care and hospice and aid in dying laws, as well as changes in institutional and doctoring practices to promote individual choice.

The well-timed death, in these discourses, seems to be one of the patient’s choosing that, theoretically, fits with their individual life. As mentioned, the ideal of choice in dying is built directly on the foundations of the patient autonomy movement and its acceptance in medical institutions, but advocates recognize that medical decision-making surrounding end of life is especially fraught. Furthermore, the majority of dying people, at some point in their trajectory, will not be able to make decisions on their own (IOM, 2015, p. 119). Advance care planning has been promoted as the way to get around this. By considering and discussing end of life care wishes, values and goals with healthcare proxies, loved ones and healthcare providers, the goal is that

decisions in-line with the patient's wishes can be made even in situations where the patient is unable to make them themselves.

There are a number of groups dedicated to raising awareness about the importance of advance care planning and working to remove barriers to its completion. For example, The Conversation Project began in 2012 with the goal of encouraging and supporting people in having advance care planning conversations. The website hosts a general starter kit in thirteen languages, which first poses questions about a person's wishes for how involved they would like to be in the medical decision-making process, how involved they want loved ones to be, and prompts users to consider their values at end of life, and so on, and then offers recommendations for discussing those with loved ones. The starter kit is intended as a way to begin what should ideally be a series of conversations with loved ones and healthcare providers about nuanced and evolving values and preferences at end of life. The Conversation Project also offers starter kits for people with loved ones suffering from Alzheimer's or dementia and kits for people with children facing life limiting illnesses, as well as guides for selecting a healthcare proxy and speaking with your doctor about your preferences. In addition, the website also includes resources for healthcare providers to improve their comfort and skill with end of life communication. The goal of Conversation Project, and many of the other advance care planning advocacy groups,<sup>24</sup> is to facilitate a difficult and complex process, fraught with uncertainty and emotion, to make having these conversations a little easier so that, ideally, everyone will have put some thought into their own wishes and share those with others before they are in a crisis situation.

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<sup>24</sup> See National Healthcare Decisions Day website for a list of advocacy groups: <https://www.nhdd.org/public-resources#where-can-i-get-an-advance-directive>

The movement for aid in dying gained momentum in the 2010s as well. Support for medical aid in dying (also known as physician-assisted suicide) has consistently been high, with little change in the percentage of people who response that it is ‘morally acceptable’ in Gallup’s polling over the past nineteen years (2019). Despite this, legislation has come slowly. Following Oregon in 1994, Washington was only the second state to legalize medical aid in dying in 2008. Since then, however, seven other states have followed suit and fifteen others are currently considering legislation (compassionandchoices.org, n.d.). Brittany Maynard’s high-profile decision to move from California to Oregon to end her life through the State’s Death with Dignity Act in 2014 offered visibility for the movement and sparked the passing the End of Life Options Act in California within a year (compassionandchoices.org, n.d.). Resistance to these laws – primarily from Catholic and other Christian organizations, as well as disability rights activists – has waned, at least in part because even after legislation is passed very few people actually take advantage of the option, negating arguments about a slippery slope toward abuse (Span, 2019). While many advocates for well-timed dying worry that increased access to aid in dying will be treated as a cure-all for all end of life issues – weakening support for increased access to hospice and palliative care, shared decision-making, advance care planning and so on – the arguments for aid in dying center primarily on expanding individual choice at end of life (compassionandchoices.com, n.d.).

In general, there has been a recent increase in circulation of physician narratives about end of life (Kopelson, 2019). In addition to the aforementioned *Being Mortal* (Gawande, 2014) and *When Breath Becomes Air* (Kalanithi, 2016) – unique in that the Kalanithi was both a neurosurgeon and dying of lung cancer while writing – there have been a slew of other books: Volandes’ (2015) *The Conversation: A Revolutionary Plan for End of Life Care*, Zitter’s (2017) *Extreme Measures: Finding a Better Path to the End of Life*, Warraich’s (2017) *Modern Death: How Medicine*

*Changed the End of Life*, Miller's (2019) *A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death*,<sup>25</sup> and Puri's (2019) *That Good Night: Life and Medicine in the Eleventh Hour*. While, *A Beginner's Guide to the End* – co-written by BJ Miller, palliative care physician, former hospice director and triple amputee of TED Talk fame (2017) – is more of a how-to guide on managing practical tasks at end of life, the others all center on medical experiences of end of life, generally arguing that the over-medicalization of dying has resulted in bad deaths. These arguments mirror Kübler-Ross' (1969), and others', criticism that medicine had turned toward the prolongation of life at the expense of caring for human suffering (p. 10).

These works, and other op-eds, newspaper and magazine articles, editorials, blog posts and so on, argue not only for cultural changes surrounding end of life – for individuals to realize that there may be fates worse than death and to begin preparing for their own deaths, as well as those of their loved ones – but also for institutional changes in the way medical facilities and insurance companies approach end of life. They tend to make the case for the benefits of palliative and hospice care in the pursuit of patient-centered care that honors individual wishes up until the end. In the process of making these arguments, they also rearticulate and perpetuate particular images of good and bad dying, many retelling narratives of patient deaths. In addition, explicitly or implicitly, they draw on notions of the U.S. as a nation in denial about death – in which many ignore the fact of their mortality and suffer overly medicalized and professionalized deaths as a result – and a medical system that is not designed with the good death in mind.

Together, the goals of the death positive movement and of advocates for well-timed dying are for people to accept that they will die and to live, prepare and, insofar as they are able, time it accordingly. These arguments for death acceptance build on the outcomes of the death awareness

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<sup>25</sup> Co-written with Shoshana Berger, editorial director at the design company IDEO.



movement – especially the development of hospice and palliative care, the discursive framings of the medicalization and denial of death and their visions of death as a natural part of life and the ideal of the good death – seeking to counter denial and taboo with conversation and cultural and institutional change. The version of the good death circulating within these discourses is based on that of the death awareness movement but centers more on acceptance of death in everyday life and at its end in the pursuit of well-timed dying. In Chapter Two, we turn to examine a set of narratives of bad and good deaths told and retold in support of these goals.

### 3.0 Chapter Two: Narratives of Good and Bad Deaths

The end of life narratives told in support of well-timed dying that are the focus of this project are told for persuasive purposes. They not only help illuminate something about the authors' experiences with death and dying, but are also an attempt to influence how others understand and approach death and dying. While these narratives have a range of specific focuses, in general they all take issue with the ways that patients, loved ones, practitioners and/or medicine as an institution approach end of life and are aimed at changing those approaches. The concept of the good death thus functions as an ideal to strive for in these stories. I argue that these narratives, all authored by healthcare practitioners, focus either on type of treatment, the role of the patient and/or on broader social and structural issues, forwarding a collective ideal of the good death that results from low medical intervention and in which uncertainty is minimized, the patient retains agency as long as possible and the social needs of patients and loved ones are met.

As noted in the Introduction, I was struck by the fact that many end of life discourses make use of narratives. These narratives can be understood as attempts to invent new narratives for end of life. In *The Wounded Storyteller*, Arthur Frank (1995) details prevalent genres of illness narratives, one of which is the restitution narrative – essentially the narrative of recovering from illness. For many illnesses which patients and their doctors face, this narrative is reasonable. However, the restitution narrative doesn't hold for chronically or terminally ill patients (p. 95). Citing a conversation with a physician who lamented the way a particular patient's life was ending – involving high medical intervention, which the doctor believed would be futile – Frank observes:

Obsessed with cure, medicine cannot place the woman's story in any other narrative [other than the restitution narrative]. Massive resources are expended, and, more important from

the perspective of my physician friend, his patient is not being helped to find her way toward her own version of a good death. Medicine's hope of restitution crowds out other stories. (p. 83)

Patients, loved ones and practitioners alike, then, need new types of stories to help make sense of contemporary medicalized dying and, in particular, narratives that align with common understandings of the good death.

The narratives told by medical practitioners as part of *NYT*'s 'The End' and those published by Gawande (2014) in *Being Mortal* give images of both good and bad dying. In general, the versions of the good death promoted within align with broader literature on the ideal of the good death, overviewed in the previous chapters. There are some additional narrative similarities to note in the texts as well: The primary characters involved are patients and healthcare practitioners, with some narratives including loved ones. With only a handful of exceptions, there are only two settings: the hospital – exam room, patient's room, ICU or doctor's office – or the dying person's home. Lastly, there are two types of events that drive the plots of these stories: medical events and those responding to medical events. Medical events, such as diagnosis, treatment, changes in a patient's medical status and so on, are part of medical knowledge-production and, generally, acts of medical agency. In response to this medical agency, patients and/or their loved ones engage in acts of ignorance-management: medical decision-making, goal-setting, adjusting to and managing new medical or physical situations and so on.

These similarities are possibly related to the fact that healthcare practitioners are narrating the stories; they represent a decidedly medical perspective on dying and approaches to end of life. It is from this explicitly medical perspective that the authors describe and evaluate the courses of events. These evaluations not only explicate but actively participate in the creation of normative

understandings of the good versus bad death. The generalized principles of the good death that these narratives reflect and reinforce are only partially applicable to actual, individual deaths, thus requiring further narrativization to explicate the good death.

In order to illuminate these narratives and the concept of the good death constructed within, I identify a critical typology of end of life narratives. By organizing the narratives into general types, the similarities and differences across the narratives come into relief, enabling me to identify how bad versus good deaths are characterized, how the uncertainty inherent in dying is dealt with and the roles of medical knowledge and practitioners at end of life. As noted, I found the narratives to primarily focus either on type of treatment, the extent to which the patient is able to control those treatment choices, or on broader structural or social issues. Within each of these focuses, there are stories of both good and bad deaths; I have thus identified six general types of narratives. There are (1) narratives of highly invasive treatments – typically curative treatments which are intended to alter the course of the disease and to prolong life – and (2) narratives of minimally invasive treatments – or comfort care, which privileges managing symptoms but is not aimed at curing, altering the progress of the disease nor necessarily prolonging life. An alternative way to characterize these courses of treatment is that highly invasive or curative treatment is undertaken with the understanding that the patient is sacrificing time now – spending it on treatment, recovery, managing side effects, and so on – for the chance of gaining more time later; whereas minimally invasive treatments, or comfort care, privileges now. There are also (3) stories of patients unable to exercise control over the treatments they receive, (4) stories in which patients are able to define their own end of life goals, (5) stories in which broader life circumstances interfere with managing the work of dying and, lastly, (6) stories that highlight the importance of social needs at end of life.

Narratives of each type offer a set of ‘lessons’ about good versus bad deaths. In the predominant narrative view within this archive, I argue a good death is primarily dependent on the type of treatment the patient chooses and upon the agency of the patient – with the ideal being a patient who chooses low medical intervention and clearly defines their own end of life goals and wishes. Additionally, it is clear from the narratives that managing the uncertainty inherent in illness and dying is a further element of the good death, which isn’t generally discussed in literature on good versus bad deaths. However, the majority of the narratives limit uncertainty to the dying person and their loved ones, covering over uncertainty surrounding medicine and medical knowledge. From this dominant narrative view, then, the role of the practitioner is to provide information to uncertain patients and their loved ones, such that they are then able to make appropriate decisions. There are two narratives that challenge this generalization, though, demonstrating that end of life decision making is not just a matter of acting on pre-given medical information and that medicine is not, and should not be, insulated from the patient.

In what follows, I identify and describe each type of narrative in turn, offering some observations about the conceptualization of the good or bad death within. Next, I overview the conceptualization of bad versus good dying found within the narratives in general, including the goal of mitigating uncertainty. Finally, I end with the two narratives that are something of outliers and consider how they challenge the predominant views in these narratives, especially with regard to the role of the medical practitioner at end of life.

### 3.1 Part One: Typology of End of Life Narratives

#### 3.1.1 Narratives of Highly Invasive Medical Treatments

There are three primary characteristics of stories about deaths involving high intervention. First, these stories are about ugly deaths. Deaths resulting from high medical intervention are frequently described as ugly and/or full of pain and suffering: “Depending on how aggressively the patient is being treated” death can be “gruesome,” writes Warraich (2015), recounting a particularly gross experience performing CPR on a patient with a hole in their abdomen from dialysis treatments out of which fluid sprayed with every chest compression. Warraich goes so far as to describe the scene as a “macabre theater,” which continues until “the supervising physician decides to call it off.” Gawande (2014), describing the final day of a young mother dying from lung cancer, sums it up: “There is no prettifying death” (p. 189). In these types of stories, dying is difficult to witness, and presumably to live through, usually (though not always) as a result of the invasive medical treatments themselves.

Second, narratives of high medical intervention also tend to focus on the risky or futile nature of the treatments themselves. Risky procedures are those with low odds of helping the patient move toward their larger goals and high probability of leaving the patient worse off. For example, Gawande begins *Being Mortal* with the narrative of Joseph Lazaroff who, following his wife’s death, swore to his son that he didn’t want to die as she had: a prolonged death with extended time on life support (pp. 4-5). However, years later when faced with metastatic prostate cancer, Lazaroff told doctors and his son that he wanted everything possible done to keep him alive: “Don’t you give up on me. You give me every chance I’ve got” (p. 4). Lazaroff underwent a risky surgery and, while the procedure was technically a success, as they removed the tumor from his spine, he

never fully recovered and died two weeks later after suffering respiratory failure, infection, blood clots and bleeding (p. 5). Gawande is still struck by this case many years later not necessarily because he believes the patient choose badly but because, according to Gawande, at least part of the reason Lazaroff chose as he did is that none of the doctors spoke frankly about his situation (p. 5). The surgery had little chance of restoring Lazaroff to anything like the life he had known and had great risks of a prolonged, painful death. Yet none of his medical team was comfortable having a conversation laying out so plainly that, in all likelihood, the life he had known was over. They presented him with treatment options, warned him of the risks, acquired informed consent and did what he wanted. In the end, Lazaroff underwent a course of treatment with significant risks of “both worsening and shortening his life” (p. 4).

In a particularly extreme example of futile treatment, Zitter (2015, Feb.) tells the story of her encounters with an elderly patient, Vincent, who was suffering a gruesome death as a result of his medical treatment. Vincent was a nursing home patient and a “frequent flier” in Zitter’s ICU:

He would come in dying, we’d plug him into life support, treat his infection, pump up his blood pressure and send him back to the nursing home. But then he’d deflate like an old tire and be rolled back in by paramedics within anywhere from three days to three weeks. By this time, Vincent was no longer competent – the only signs of consciousness coming with moments of intense pain which “fired up dormant neurons and his blue eyes flared” – but he had filled out an advance directive ten years prior, in which he stated that he wanted all attempts made to prolong his life. In addition, a handwritten note stapled to the form left no room for doubt about his wishes: “I want you to do EVERYTHING in your power to keep me alive AS LONG AS YOU POSSIBLY CAN.” Zitter and the other ICU doctors and nurses followed Vincent’s wishes and combated each new issue as it arose – often creating new problems with each fix – doing their best

to “keep his body going even when it was trying it’s hardest to die.” Eventually Vincent “was suffering, with every terrible dressing change, every lonely hour in an I.C.U. isolation room,” with “all of his grit drained from his body.” Zitter’s description of Vincent’s physical condition is worth quoting at length:

On [his] ninth admission, when I took over his care, I was almost unable to complete my physical exam. This man’s body was being eaten away to a degree I had never seen. Autodigested while dying. Even with the most attentive nursing care, a flaccid, dying body has pressure points where thin skin eventually breaks down. ... Vincent’s shoulder and heel ulcers were severe. But the one that stopped me in my tracks started at the low end of his spine and spread toward his left hip, melting skin and muscle away so that his entire hip socket lay open to the air. Even as a seasoned I.C.U. physician, I gasped the first time I laid eyes on it.

This death was clearly difficult for Zitter and other healthcare providers to witness. Vincent’s suffering was a result of the futile treatments requested in his advance directive. Zitter doesn’t believe that anyone would actively choose Vincent’s ending but speculates that he didn’t know what he was setting himself up for. In fact, this case leads her to “openly question our blind trust in patient autonomy.” Vincent’s medical team tried to address the most pressing medical developments but weren’t able to do anything to change the fact that he was dying. In these stories of invasive medical intervention, a death is characterized as bad primarily as a result of the pain and suffering inflicted on the patient, though it clearly impacts caregivers, as well.

The third characteristic of narratives about invasive interventions at end of life is that they feature prolonged deaths. Prolonged deaths are those in which the dying process is extended via medical interventions that have low probability of curing the patient. In many of these cases, the



biological life of the patient is extended but often at a low quality of life and only for the sheer sake of prolonging the persons' life. As with Vincent above, in these narratives treatment is undertaken with little hope that the patient will recover, rather they seem to serve primarily to delay the inevitable, usually with negative impacts on patients, healthcare professionals and/or loved ones. In another example, McConnell (2015), an ICU nurse, recounts the story of an elderly stroke patient in her ICU who was weak, unwell and having difficulty breathing, but otherwise in stable condition. The patient's family knew about his condition and were considering changing his status to 'do not resuscitate/do not intubate' but had not yet decided. From McConnell's perspective, it was clear that he would not make it out of the ICU and, furthermore, that available treatment options were not helping, but rather keeping him in limbo while the family decided when to remove life support. Importantly, for McConnell it was a question of *when* to remove life support, not whether or not to do so. The patient was eventually intubated: "a hard plastic tube pushed through his mouth down his trachea, taped to the delicate skin of his face." Shortly thereafter, the man's family gathered and, finally witnessing first-hand the life sustaining measures that keep a dying person 'stable,' decided to withdraw life support. This patient spent two weeks in the ICU unconscious and slowly deteriorating before his loved ones decided to allow him to die by removing life support. According to McConnell, this occurs all too often, with many families treating the ICU like a 'pause button,' opting for a patient's life to be sustained via increasingly intensive intervention before eventually permitting death:

Families should realize that this time is the end of life, and they should pay attention to its quality just as they would if the patient were dying at home. That's because although we can usually hold off death, we cannot pause time, and an extended stay in the I.C.U. is an ugly way to end a life.

McConnell refers to the “eerie dehumanization” of both patients and caregivers when loved ones don’t recognize that the patient is dying, using this narrative to plead with families to relieve ICU doctors and nurses of their legal duty to prolong life regardless of anticipated quality of life. Even when a prolonged death is not directly causing suffering, dying that is prolonged via invasive interventions without hope of recovery is characteristic of bad dying, in part, because of its effects on caregivers and loved ones with minimal benefit for the patient.

In the narrative view, uncertainty surrounding when the dying person has entered the nebulous state “end of life” may result in treatments which not only prolong dying and may actively make the patient worse, but also interfere with their ability to perform their dying role. For example, Sara Monopoli, a new mother with aggressive lung cancer, made it clear to her husband and family that she wanted to die peacefully at home (Gawande, 2014, pp. 165-66). However, in meetings with her medical team there was no discussion of comfort care or of stopping treatments. Despite knowing intellectually that her disease was incurable, the entire family, patient included, remained in “battle mode” (p. 168) until, eventually, her primary care physician intervened with concerns about the increasingly invasive and frequent medical interventions. As her husband put it after she died, he didn’t know how to act on her wishes, it didn’t seem possible for them: “I always wanted to respect her request to die peacefully at home,” he told Gawande. “But I didn’t believe we could make it happen. I didn’t know how” (p. 172). As a result, they opted for each treatment offered, no matter the likelihood it would result in a desired outcome – either altering the course of the disease or dying peacefully at home – and no matter the risks. In the end, they never had a chance to say goodbye, reach some measure of closure or do any of those things that can make dying meaningful for the family. The courses of treatment they opted for ended up taking time away from Monopoli and her family. Gawande, who was part of her medical team,

stated: “In the previous month, almost nothing we’d done to Sara – none of the scans or tests or radiation or extra rounds of chemotherapy – had likely achieved anything except to make her worse. She may well have lived longer without it” (p. 189). In this case, while the patient and family were, in theory, clear on the patient’s preferences for end of life, none of them knew how to achieve those preferences because it was never obvious when it became time to prepare for her death, instead of continuing curative treatment. As a result, Monopoli suffered a long, slow and painful decline.

Stories about high medical intervention at end of life tend to focus on the pain and suffering of the dying person, the futility or riskiness of the treatments themselves and/or the difficulty of recognizing or perhaps accepting when a person is actually dying, which often leads to prolonged dying. The clear message in these narratives is to avoid this type of ending. By and large, patients undergoing invasive, curative treatment are generally described as passive – they are *undergoing* treatment, treatment is being *done to* them. For some, it seems to be in part because the patients are unconscious in the narratives – Vincent and the unnamed elderly ICU patient, in particular (Zitter, 2015, Feb.; McConnell, 2015). Sara Monopoli (Gawande, 2014), on the other hand, was conscious for the majority of the narrative and furthermore described as being in “battle mode,” which on its own seems like an active state of being. But in this narrative, battle mode means taking every treatment option there is, seemingly, without consideration of outcomes. There was no discussion of end of life goals, no indication of shared decision-making, no weighing the risks of treatment versus possible benefits in this narrative. Monopoli and her family are depicted as opting for treatment after treatment, almost blindly, while Sara herself wasted away. In contrast, Lazaroff was conscious and was described as actively choosing his course of treatment. In Gawande’s assessment, Lazaroff simply chose poorly and ended up with what was statistically

most likely: a shortened life and a painful death. The goal, then, seems to be a death in which the patient has some agency at end of life – a patient who acts versus being acted upon – and uses that agency to make (what doctors view as) good decisions. The majority of the time, it seems the “right” decision is to opt for lower intervention.

There is another narrative that makes this point clearly. In this story, a proxy decides that doctors should perform a tracheostomy (in which a breathing tube is sewn into the neck) on her adult daughter (Zitter, 2015, Oct.). The patient, Michelle Moore, came in with an infected heart valve from bad heroin. Her muscles, vital organs and brain were threaded with pus from the infection – to such an extent that her hands and feet were dying and her brain was bleeding. The medical team treating her, Zitter included, had been sure that she would not recover and counseled the family as such:

I presented Michelle’s mother with both options: Withdraw the breathing tube and allow her to die, or replace it with a trach and keep her on machines. When they asked me what I would do if this were my family member, I said I probably would not perform a tracheostomy. Still, her mother, a religious woman, decided she would hold out for a miracle. And so against my better judgment, we trached her.

For the first several months following the procedure, the doctors and nurses treating Moore viewed her as an unfortunate example of non-beneficial life prolongation. That is, until she woke up and, in time, made a remarkable recovery. Zitter was struck by doubt following the patient’s recovery: Did she make a mistake counseling the family to withdraw life support? Has she made this mistake in the past? Will she be able to deliver news of poor prognosis or expected outcomes in the future? Should she? Eventually, Zitter concluded that she can count on one hand the number of times she

has witnessed a miracle like the one in this narrative and so, while the unexpected can happen, the more likely outcome is extended time on life support without hope of recovery.

The fact is, there are two types of risk in cases like these. One risk is that a patient will be deprived of the chance at a miracle. But the far more likely risk is that a patient with no chance of recovery will become permanently attached to machinery designed to automate breathing and feeding, and spend the rest of her life in a nursing home, being washed by strangers, enduring infections and skin breakdown, family visits ebbing because it's simply too painful. Survey after survey shows that most people would never choose this path.

While this narrative is not technically about end of life, as the patient survived against the odds, Zitter uses it to make a point about end of life issues: that most people won't get a miracle and the risks are too high to take the chance. Zitter never outright says that Moore's mother chose badly – and indeed Zitter is almost moved to tears when Moore is discharged – but she does make clear that, statistically, it was not the right choice. This conclusion only makes sense if you approach the situation as a doctor, rather than as a dying person or as the loved one of a dying person. This statistical view considers mortality – which is to say, dying at the population level – whereas a person facing their imminent demise, and/or that of their loved ones, are invested in this particular death; they're concerned with *dying* (or not dying as the case may be) not *mortality*. Approaching end of life from the viewpoint of mortality, the “right” choice is to cease curative care – at the proper time – in favor of comfort care, to forgo non-beneficial life support and to accept that the patient will die. Narratives about high medical intervention that leads to bad deaths, as well as some of the other types we'll see, attempt to persuade readers to at least consider, if not outright adopt, this statistical view when approaching end of life, in order to achieve a well-timed death.

### 3.1.2 Narratives of Minimally Invasive Medical Treatments

Stories about low medical intervention at end of life demonstrate three characteristics of the good death, which are made possible by choosing comfort, rather than curative, care. First, end of life is consistently described as peaceful, at home surrounded by people (or things) the patient loved. For example, Volandes (2015) tells the story of a patient who decided not to pursue aggressive, curative treatment following a tour Volandes gave her of the ICU. During the tour, she witnessed patients on ventilators and sees CPR performed on one patient. Rather than spending her remaining time in a similar way, she opted instead for comfort care. She died a few weeks later “at home, in the company of friends and family and surrounded by her poetry books, as were her wishes.” In another example, Gawande (2014) tells of pancreatic cancer patient, Dave Galloway, who was told there was nothing more doctors could do and was given the option of dying in the ICU or going home on hospice (p. 162). Galloway chose hospice care and died “at home, at peace and surrounded by family” (p. 164).

Second, dying in a familiar setting, with the people and things one loves most is portrayed as in keeping with the life of the dying person. For example, Ms. Douglass, whose adult daughter reported: “she drifted quietly to sleep and took her last breath. It was very peaceful. My dad was alone by her side with the rest of us in the living room. This was such a perfect ending and in keeping with the relationship they shared” (Gawande, 2014, p. 242). Deaths of these sorts are characterized as what the person (would have) wanted and, at least in the narrativized version, the patient dies without struggle and is as comfortable as possible. Often, these good deaths are peaceful for the surviving loved ones and healthcare providers as well.

Third, this type of death is depicted as more meaningful for loved ones. Gawande retells a narrative shared with him by an oncologist who was treating a 29-year-old man with an inoperable

brain tumor (pp. 185-7). After a second line of chemotherapy failed to stop the tumor's growth, this doctor had several lengthy meetings first with the patient, then with the patient and his family together, and finally one-on-one with the patient's father. The patient initially came into the oncologist's office expecting to schedule a third type of chemotherapy but the oncologist did her best to communicate the very low odds that this therapy, the last option she had to offer, would actually extend his life. They discussed what was likely to happen as the disease progressed, as well as the side effects and anticipated outcomes of the treatment. The oncologist saw the patient slowly realizing that he was, in all likelihood, nearing the end of his life and that the remaining treatment options were not going to improve his health or extend his life. While he was able to adjust to this information, it took an additional meeting with his family for his wife and mother to accept it. The patient's father required even more convincing and the oncologist visited the father at his home to review the experimental treatment options he had researched. The oncologist patiently explained why each one was not a good match for his son. The turning point came as the oncologist told him "he needed to understand: time with his son was limited" and the patient "was going to need his father's help getting through it" (p. 186). As a result of these conversations the patient chose hospice rather than continuing curative treatment, the family successfully transitioned out of 'battle mode' and they were able to spend the last month of his life together without side effects from treatment impeding interaction. After the patient's death, his father thanked the oncologist for helping them to understand the situation and convincing them to spend the time as they did. "That last month," the father said, they "simply focused on being together, and it proved to be the most meaningful time they ever spent" (p. 187). In order to have that time together, though, patient and family had to first accept that he was dying and shift treatment goals accordingly.

In the narrative view, the end of life for people who decide to stop treating their disease is peaceful and allows for a death that is fitting to their life. As we'll see below, comfort care creates time for the dying person to take up the dying role and for the dying person to spend time with loved ones. End of life can then be fulfilling and meaningful for patients and/or loved ones, but only once the decision to stop curative treatment and accept that the person is going to die has been made. Low intervention doesn't *necessarily* make for a good death on its own – there may be other circumstances that intervene – but it is worth noting that there are no narratives, in this archive at least, in which people who opt for low interventions are depicted as suffering a bad death.

Interestingly, the timing of the decision to forgo curative treatment is rarely discussed directly in the narratives. As all end of life decision-making eventually comes down to the decision of when to stop treatment and allow the patient to die, the *timing* of that decision is a key element in whether the death is characterized as good or not. That a 'prolonged death' is characterized as bad results from the timing of the death relative to the social death of the patient – the death came 'too late,' as Kellehear terms it (2007). That the decision to stop treatment in order to spend remaining time with loved ones without the side effects of treatment interfering, for example, is characterized as a good has to do with the timing of that decision – too little remaining time and the decision came too late; on the other hand, one can also imagine that decision coming too soon if there was perhaps more benefit to be gained from curative treatment. The timing of the 'well-timed death' is thus based on the individual medical and life context of the patient. As such there is a *kairotic* element to the decision to stop treatment and to permit death. The choice between curative and comfort care is a major focal point in these narratives, and that choice is a major source of uncertainty for patients and loved ones, but the *timing* of that choice is almost always based on medical knowledge. Which is to say, the bifurcation moment between curative treatment



and comfort care is determined by practitioners – who present the choice to patients to decide after a medical event or following completion of a round of treatment, for example – rather than being shaped by the individual’s social context.

### **3.1.3 Narratives of Patients Unable to Exercise Control Over Treatments**

The third type of story told in these texts are those in which the medical treatment received does not align with the patient’s wishes. Some narratives depict situations in which the dying person is unconscious and their wishes unknown. In these situations, a proxy is selected to make decisions, ideally in the best interest of the patient. In Periyakoil’s (2015) article ‘Pitfalls for Proxies,’ she recounts two narratives of patients whose wishes are unknown and whose treatment choices are left to loved ones. In both of these stories, according to Periyakoil, the proxies made poor decisions based upon their own needs rather than those of the dying person. In the first example, a patient without an advance directive contracted an infection after chemotherapy. He was admitted to the ICU but, despite intensive treatment, his condition continued to deteriorate. However, his wife would not consider withdrawing life support. Finally, Periyakoil asked the wife if she would want this same treatment, were their positions reversed: “Of course not, she said. She would want to just die peacefully. So why was she subjecting her husband to this fate? ‘*The duty of a good wife is to save her husband,*’ she said softly and with steely determination” (emphasis in original). As Periyakoil describes it, the wife did not consider what would be the best outcome for

her husband – nor show any interest in pursuing what Periyakoil seems to consider a good death – but instead makes decisions based on her idea of how a good wife should act.<sup>26</sup>

In the second example, Periyakoil recounts a story of an old man dying in the ICU. Hospital staff eventually track down the patient’s son, John, who has not visited his father for several years. Despite being estranged, John becomes his father’s proxy by default and doctors ask him for permission to withdraw life support. John declines. According to Periyakoil, John was moved by the thought of all the time he had missed with his father and so was “primarily motivated by his own need to have one last opportunity to repair the broken relationship and make amends to redeem himself.” The proxy heeding the “call of redemption” – or the “call of duty,” in the example above – results in overtreatment and a prolonged death, and thus, according to Periyakoil, both are to be avoided by carefully naming a proxy in advance and making your wishes clear to that proxy.

Even in cases where a person’s wishes are known, they can be outright overruled by their proxy. Periyakoil further tells of Carl, who used his power as proxy to override his partner, Darlene’s, ‘do not resuscitate’ (DNR) status. Darlene had advanced lung disease and a bad case of pneumonia resulting in respiratory failure and loss of consciousness. Following what Periyakoil named the “call of love,” Carl, “who could not imagine life without Darlene,” made the decision to have her resuscitated. Darlene was furious at Carl for not allowing her to die ‘naturally:’ “How can I ever trust you again?” Darlene asked Carl after waking up and learning what had happened. However, Carl maintained that he had saved her life. Periyakoil’s telling of the narrative does not give a sense of Darlene’s actual death, but Periyakoil clearly thinks Carl was in the wrong in this situation and uses this narrative in an attempt to persuade readers to choose carefully when

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<sup>26</sup> It is worth noting here that the patient and wife in this scenario are Korean-American and Periyakoil paints the wife as a stereotypical woman of Eastern Asian descent: “Soo-jin was a soft-spoken woman who was respectful and deferential to the doctors.”

selecting a proxy, noting that a close loved one may not be able to make the best decisions precisely because of their love for the patient.

In these narratives there seems to be little consideration of the potential needs of the proxy, or other loved ones, in end of life situations. As discussed in the Introduction a good death is co-constructed by dying people, their loved ones and healthcare providers. Many have argued that the characterization made by the dying person themselves is the most important (see Scarre, 2012), but endings do impact loved ones as well. Proxies and healthcare providers have to live with the choices they make on behalf of dying people. Periyakoil only takes the (assumed) perspective of the dying person – which seems to align with her own views on the good ending to life – into consideration in these narratives, without taking seriously, for example, the contextually-bound logic driving of the duty-bound wife or the estranged son.

Lastly, there are stories about medical interventions not in accord with patient wishes that result from loved ones being unsure how to respond to medical crisis. For example, Zitter (2015, April) tells the story of an 86-year-old with a chronic heart problem whose wife calls the paramedics when he collapsed at home. The patient had filled out an advance directive and had “adamantly, repeatedly, and clearly told his family he wanted no more of it. No more shocks, no more hospitalizations, no surgeries or catheterizations, no pacemakers.” His daughters arrive at the ICU a short time after the patient has been stabilized and are, understandably, very upset that his wishes had not been followed. Zitter explains that while the patient’s efforts at advanced decision-making were good, an advance directive does not relieve first responders of their legal duty to sustain life once called. She gives the family the correct form for the patient’s situation and sends them home with the proper documentation to ensure that the patient’s wishes are respected, whether or not he is able to directly communicate them in any future situations. This narrative does

have a happy ending because the mistake is corrected such that his wishes were ultimately respected: “We sent him home on hospice, Polst [form] in hand, to be with his family for the precious time he had left – to live, this time protected from the type of death he feared the most.” In this narrative, it seems that the patient’s wife had not intended to overrule his wishes but had not known how to ensure that he had “no more of it” given the medical crisis. Without knowing that paramedics are legally obligated to prolong life unless they have a physician’s order not to, she may not have known that she was going against her husband’s wishes by calling 911 when he collapsed. Interestingly, we don’t see any more of her perspective in the narrative, Zitter only narrates interactions with the patient’s daughters.

The lesson of these types of stories is first, to be clear on your wishes and second, to pick your proxy well – you want someone who will follow your wishes and, ideally, has enough medical literacy to see them through. It is telling that the proxies in each of these narratives make the decision for *more* treatment, even if unintentionally. In each case, these proxies chose such that the dying person was subjected to further curative treatment and their lives were prolonged. The authors make clear that rather than defaulting to more futile or risky treatment, proxies should be protecting their loved ones from that type of death. Again, the moral of these stories is that minimal intervention at end of life, especially when the patient is passive and cannot choose for themselves, is better.

### **3.1.4 Narratives of Patients Able to Shape End of Life Treatments**

The fourth type of narrative depicts patients who define their own goals at end of life and have caregivers who are able to help carry those out, to the extent the evolving medical situation allows. They tell the stories of patients who are able to make decisions about their care at end of

life, ideally defining a good death for themselves, almost all of whom make the decision to stop curative treatment. There are a few different characteristics of this type of story. First, it is up to the patient to determine and communicate their wishes, often at the prompting of loved ones or medical team. This can be a difficult and even awkward, as in two narratives Gawande (2014) tells of adult children going through the process of determining their parents' treatment wishes. In the first, palliative care specialist Susan Block left her father's house the night before he was scheduled for surgery on a mass in his spinal cord, when she realized that, despite being his designated healthcare proxy, and a palliative care specialist, she didn't know what his wishes really were (pp. 183-85). She turned the car around and returned. "Going back in 'was really uncomfortable,' she said. It made no difference that she was an expert in end-of-life discussions. 'I just felt awful having the conversation with my dad'" (p. 183). She asked what he was willing to endure in order to stay alive, what minimum quality of life he imagined would be tolerable. His response – so long as he could watch football and eat chocolate ice cream, he would be happy – astounded Block, who'd never known her father to watch a football game (p. 183). As it happens, there were complications after his surgery the next day and Block had three minutes to decide whether to authorize an additional surgery to stop bleeding in her father's spinal cord, a procedure which might save his life but would leave him nearly quadriplegic (p. 184). There was no decision for her to make, she realized; he had already made it. When asked, the surgeon confirmed that her father would still be able to watch TV and eat ice cream even if he became quadriplegic as a result of the second surgery. Block says that without the conversation with her dad, her instincts would have been to permit him to die instead, but either way she would have agonized about it. He lived another ten years after that surgery, before the trade-offs became too great for him and he decided to stop curative treatment for his condition and died at home on hospice care (p. 184).

Gawande himself went through a similar experience with his own father. Sitting down with his parents to discuss treatment options for the tumor in his father's spinal cord, Gawande asked his father the very questions he'd learned to ask patients from Susan Block: What did he understand his prognosis to be? What were his concerns about the future? What kinds of trade-offs was he willing to make? How did he want to spend his time if his health got worse? Who should make decisions if he was unable? (see pp. 182-83):

Those questions were among the hardest I'd asked in my life. I posed them with great trepidation, fearing, well, I don't know what – anger from my father or mother, or depression, or the sense that just by raising such questions I was letting them down. But what we felt afterward was relief. We felt clarity. (pp. 212-13)

Referencing the story Gawande had told him about Block's father, Gawande's own father responded that watching TV and eating ice cream would not be enough for him to feel fulfilled. He wanted to be able to remain social, to continue to influence his life and those around him.

In these stories, the dying people are able to determine what minimum quality of life would be acceptable to them at end of life – which is to say they are able to identify what they value most about living. They and their loved ones use that information to guide medical treatments in situations where the patients were not able to speak for themselves. In both cases, it is as though the dying person had already made the necessary decisions, though this may not always be the case even when loved ones have end of life conversations. There are also times that the dying person may need help in determining those goals or even seeing the point of making goals at end of life at all.

Gawande tells the story of Peg Bachelder, his daughter's piano teacher, who, after years of misdiagnosis, was finally diagnosed with soft-tissue sarcoma. After about two years of treatment,

Bachelder developed a “leukemia-like malignancy caused by her treatment” that stopped responding to intervention (p. 246). Speaking with Peg on the phone while she was in the hospital, Gawande reports that she sounded flat and hopeless after doctors had stopped chemotherapy: “I asked her what her understanding of her condition was. She said she knew she was going to die. There’s nothing more they can do, she said, an edge of anger creeping into her voice” (p. 247). Gawande asked next about her goals, but she couldn’t see any point in future goals, even for the proximal future. When asked about her fears it was clear that her anxiety was overwhelming her: “She choked up as she spoke. She’d been there [in the hospital] for days just getting worse, and she feared she didn’t have many more. I asked her if they’d talked to her about hospice. They had, she said, but she didn’t see what it could do to help her” (p. 247). Gawande explained that the goal of hospice is to work toward one good day and encouraged her to at least talk to them. Peg agreed that a good day was worth hoping for and went home on hospice within two days. Rather than focusing on medical treatments or altering the course of the disease, the hospice nurse asked how Peg wanted to spend her remaining days, what she cared about most (p. 248). Working toward these concrete goals, Peg’s anxiety and hopelessness dissipated as the challenges of daily life and her symptoms were both managed. She was able to teach piano lessons for the last month of her life and, according to Gawande at least, Peg “fulfilled her dying role” (p. 249), as she was able to live as a dying person and fulfill other relational roles, reach some measure of closure with her students and adjust to the inevitable loss (see Emanuel et al., 2007). This was only possible because Gawande played the role of both doctor and friend, and was able to nudge her in what turned out to be the right direction. This narrative in particular does not gloss over the fact that dying can be overwhelming, that it may not be easy to accept that you’re dying and to decide how to live your

remaining days. This task may be especially difficult if all of one's energy has been focused on beating the disease; it can make taking up a dying role seem pointless or impossible.

The preceding examples also illustrate the second characteristic of this type of narrative, that the patient's broader goals for living at end of life serve as guides for their treatments. Which is to say, in the three narratives above each patient was able to decide how they wanted to live at the end of their life – eating chocolate ice cream and watching football, fulfilling obligations and directing the course of one's own life, or teaching piano lessons. These life goals, in conjunction with their medical status and/or physical state, then determined the treatments, whether curative or comfort, each of them pursued and those they declined. This reflects a change from previous conceptualizations of advance care planning, in which it was advocated that patients decide – in advance – which treatments they would want and which they didn't. The problem with this is that medical situations are too complex and evolve too rapidly for treatment decisions to effectively be made in advance. These stories reflect this shift in the literature on good deaths toward focusing on values and quality of life in shared decision-making, rather than on specific treatments.

The third characteristic of stories of patients defining their own goals at end of life is that they feature caregivers who help them work toward those goals. As with Block and her father and Peg and her hospice nurses, these types of narratives include proxies and/or caregivers able to respond to evolving medical situations and make decisions in the patient's best interests, even if not directly in accord with their stated wishes. Hospice nurse Brown (2015, Oct.), described the death of a patient that was particularly difficult for her, in part because she didn't feel she could adequately manage the patient's symptoms and honor his wishes to die at home. Brown and the patient's family thus found themselves at a crossroads, unable fulfill both his wishes to die at home and to die peacefully. She and the family decided together to have him transported to the hospital



– where managing his pain would be easier – thus privileging the desire for a pain-free death over dying at home. However, it was the middle of a Pittsburgh winter, roads were very icy and it took the ambulance upwards of an hour to arrive. In the meantime, the patient’s pain and distress mounted. Despite this, Brown notes in retrospect, there was a palpable feeling of love in the room from the patient’s wife, children and even the family dog. Eventually the ambulance arrived, the patient was taken to the hospital and died. While this narrative began with Brown admitting it was a difficult memory for her, by the end she has come to peace with it because the “patient died peacefully, surrounded by family – the promise of hope was fulfilled.” She clarifies, “Not hope of a cure, of course, but of pain relieved and comfort given.” Despite having no choice but to deviate from the patient’s stated end of life wishes, the patient died “peacefully, surrounded by family.” His death is characterized as good because Brown realizes that they were able to make decisions in his best interest and, importantly, because the family and caregivers, namely Brown as the narrator, come to terms with his death.

Despite things not going as exactly planned in these narratives, it seems that the dying people still maintain at least some amount of agency to decide. Block and Gawande’s fathers don’t get to make their own medical decisions in the moment, but Block and Gawande are both able to use their fathers’ end of life wishes to make decisions on their behalf. Peg Bachelder was hopeless and anxiety-ridden when no more curative treatment was offered, but, with help from loved ones and hospice, she was able to regain agency in her life and take up the dying role. Brown’s hospice patient is unable to make his own decisions about which end of life goal to privilege, but his proxies are able to act in his best interest, rather than their own, as in the narratives in the previous type. Like stories of low medical intervention – those in which patients privilege *now* instead of sacrificing time now for the chance to gain more later – these deaths are depicted as good because

the dying person is able to shape their ending, to some degree at least, in accord with their identity; their endings fit in some way with their lives. Additionally, and importantly, the other stakeholders, whether the doctor-authors or the patient's loved ones (as narrated by the doctor-author), characterizing the death retrospectively feel as though they made the right decisions.

These narratives further suggest that reducing uncertainty, whether for proxies or the dying person themselves, is a central feature of the good death. While medical situations are necessarily uncertain – by virtue of dealing with the innate uncertainties of practicing medicine on human bodies – by creating space for and respecting the agency of the dying person, the proxy acting on their behalf doesn't have to navigate that uncertainty on their own. Gawande feels relief and clarity after the conversation with his father; Block doesn't have to agonize over whether or not she made the right decisions. For Brown, the memory of this particular patient is recurrent in part because of her uncertainty of how to reconcile the patient's goals which were suddenly at odds – that of a pain-free death and to die at home. This memory is resolved for her when she remembers that the patient's loved ones maintained a loving space for him and that they did make the right decision in the end. Or in Bachelder's case, the hospice nurse helps Peg shift her focus from dying and the future she would miss out on, to living in the present. Peg's anxiety about the future reduces once her medical symptoms are controlled and she feels she is able to live at the end of her life. The ability to shape her remaining time reduces uncertainty over the course her disease will take; as her symptoms are rendered manageable, she can imagine what her final days will look like. Furthermore, taking the view of mortality rather than individual dying is an attempt to manage the uncertainty inherent in dying by narrowing one's image of the future to the most probable outcomes. In particular, what narratives of patients able to shape treatment at end of life espouse is a merging of statistical and individual views of death. Accepting the most probable outcomes,

statistically speaking, and creating space for the dying individual to live through their deaths in an individual way is held up as an ideal to work toward at end of life.

### **3.1.5 Narratives in which Life Circumstances Interfere with the Management of Dying**

The previous types of narratives focus on the types of medical treatments the patients received – highly or minimally invasive treatments – or on the role of the patient in determining course of treatment. Dying is also impacted by the life circumstances of patient, social, economic, political and so on. This is most evident in the fifth type of story, in which the authors explicitly discuss life circumstances that make achieving the ideal of the good death more difficult. For example, Crosby (2015), a doctor in a large regional ‘safety net’ hospital, details the case of an American citizen, Mohammed, who emigrated from an unnamed African country, has limited English and low health literacy. His children had recently arrived in the U.S. and he was struggling as a newly single parent, his wife’s visa delayed. Mohammed visited the author with a lesion on his head, for which she sought a second opinion and eventually scheduled a biopsy. He never made it to the biopsy because life intervened. He didn’t seem to understand the importance of the procedure and none of the medical staff noticed or followed up on the missed appointment. When Crosby saw Mohammed again for the first time, eight months after that missed appointment, his condition had deteriorated rapidly: he had been diagnosed with malignant melanoma, had undergone surgery and suffered nerve damage as a result. He died on the floor of his bathroom, 21 months after diagnosis, on the same day a hospice nurse had been scheduled to come for their first in-home visit. Crosby had been able to help expedite Mohammed’s wife’s immigration so neither he, nor his children, were on their own, but mitigating that circumstance did not seem to alter the circumstances in which he died. In this case, he fell through the cracks, and, as Crosby notes, the

medical institution itself is partly to blame. But his overall situation was ‘complicated’ by low English literacy, low health literacy and difficulty navigating unfamiliar medical and social systems, which resulted in a bad death. All of this points to the fact that there are particular social and life circumstances that make achieving the good death more likely than others.

In another example, doctor of palliative medicine, Puri (2016), tells of her first year of practice in which she visited her South LA patients in their homes. She gives a snapshot of a day, providing the details of four of her patients who lived in low-income neighborhoods, which also have some of the city’s lowest life expectancies: “In these neighborhoods people die an average of 10 years earlier than those who live less than 10 miles away. Many of my patients felt that they had barely lived their lives when I showed up, ostensibly to help them ‘die with dignity’.” In addition to the difficulties of dealing with dying ‘before one’s time,’ they also faced additional obstacles as a result of their socioeconomic realities and insurance options. First, Puri visits with Sergio, a 45-year-old man with stomach cancer who was being cared for at home by his wife, Maria, with occasional help from a neighbor. Neither Sergio or Maria had any family in the U.S., and so primary caregiving duties fell to Maria, who was responsible for managing his medication, bathing him, helping him in and out of bed, calling someone when he was in distress, and so on. Worry over her husband’s deteriorating state kept her from sleeping at night, as she feared missing a sign that his condition was worsening. Sergio was sick, but not sick enough to justify, from an insurance standpoint, admission to a hospital or other institution which would provide care and allow Maria to just be Sergio’s wife, rather than wife *and* fulltime caregiver. After seeing Sergio and Maria, Puri visited Janice, a 60-year-old with advanced breast cancer, who was estranged from her family and relied only on her landlady and two church friends to help manage her care. Then Joseph, a 50-year-old military veteran who was afraid to keep opiates in his home for fear of being

robbed. His lung cancer had spread to his bones and he needed the medication to manage pain, which had gotten so bad that without medication he couldn't walk. Puri was eventually able to convince him to try small doses of morphine, promising to help him find a secure hiding place. After Joseph, Puri visited Jorge who had Lou Gehrig's disease. His wife was the primary caregiver but she had taken on extra shifts to help make up for Jorge's lost income. On her previous visit, Puri found Jorge alone, short of breath and unable to reach his medication. He assured Puri last week that in just a couple more days they would have the money to pay for help so that Jorge would not be left alone. On this visit she gently reminded of the need for an in-home caregiver, again listing the reasons he couldn't be left alone.

It is against these odds that Puri was tasked with attempting to help her patients achieve a good death. She writes

I constantly wonder whether, given these life circumstances, my patients fully benefit from the care my team and I try to provide. Aside from assessing symptoms and providing medications to ease them, perhaps just treating what I can with compassion is the best I can do for them. Still, I try to find some meaning in these visits, in the visits that preceded them, in all the visits that await, so that I can get up tomorrow and do this imperfect work again.

This article, more so than the others, makes clear just what it takes to manage dying and that bad, or at least less than good, deaths can result from unequal access to the necessary luxuries, as Puri calls them: reliable access to medication, money or insurance to pay caregivers, a strong social network to help manage the work of dying as well as that of everyday life, a safety net to help absorb lost income when the dying person can no longer work and ideally one strong enough to allow loved ones to take time off as well, and so on. From the narrative of her day, and the details

Puri provides about the obstacles she, her team, her patients and their loved ones face, it is clear that bad dying may not necessarily be ugly or involve futile treatment but looms in the inability to secure adequate care at end of life. Dying is as much an economic and political issue as it is a medical one. All of these narratives are of people who opted for low medical intervention, who, in theory, were making the right decisions that should have resulted in good deaths, who want to the opportunity to die peacefully at home surrounded by loved ones. However, they have to manage additional uncertainty and stress surrounding medical and social issues – primarily as a result of their financial situations – making their deaths even more difficult to manage.

In an example that makes clear the extent to which medicine – and thus medicalized dying – cannot be separated from politics and economics, palliative care physician Ira Byock (2015) tells the story of a friend of his, Michael, who was undergoing treatments for cancer. Michael had exhausted all other treatment options and began a Phase I clinical trial. However, Byock was concerned that Michael’s symptoms were not being adequately managed. Speaking with the nurse overseeing the clinical trial, he suggested that Michael and his loved ones may benefit from his concurrent enrollment in hospice. “‘It’s his choice,’ the nurse said, referring to Medicare rules that require patients to choose between cancer treatment and hospice care. It was, but what a terrible choice to have to make.” Because of the Medicare rule, Michael, and other people at end of life, delay entering hospice and many suffer because of having to choose between curative care and hospice, which, significantly, means they have to first accept that they are dying and agree to forgo even experimental treatment in order for insurance to cover meetings with hospice. Byock goes on to lay out policy changes that would make dying “safer,” (i.e. alleviating unnecessary suffering, maximize independence, effectively coordinate care, manage and prevent crises, and so on). The

shape that end of life takes is intertwined with political and economic elements over which the majority of us have little to no control.<sup>27</sup>

In particular, it seems that the necessity of managing financial uncertainty is taken for granted in the majority of the narratives in my archive. The three articles discussed here are the only which include income or insurance status in the narratives. It is assumed that the dying people at the center of the other narratives can afford their treatments, whether curative or comfort. With the exception of Crosby, who assures readers that Mohammed was fully insured thus placing the blame for his bad death primarily on the medical institution and on herself, the only times financial issues are brought up is when they interfere with the management of dying. For insurance reasons, Byock's friend has to choose between an experimental treatment – which, again, was not intended to cure him – and hospice; Puri's patients run the risk of a bad death because they don't have the safety net to absorb lost income, allow family members to take time off or provide for care where their insurance falls short. In these situations, it is financial or insurance-related uncertainty that creates the possibility of a bad death. The general invisibility of this issue in the majority of narratives in my archive reinforces a particular version of dying in the U.S., eliding issues of who has access to the possibility of a good death.

It is worth further underscoring that these broader life circumstances, as I call them here, are only the explicit focus of the narrative when they function as barriers to a good death. All of the deaths included in this archive are shaped by the life circumstances – which includes the social aspects discussed in the next section – of the people involved. Those circumstances recede – or are pushed – to the background of the narrative when they set the conditions of possibility for a

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<sup>27</sup> See, for example, David Wendell Moller's (2019) overview of the impacts of recent federal healthcare and welfare policies on the deaths of poor people in the U.S. (pp. 211-229).

*good* death. Which is to say, the privileges of people who are economically, socially, culturally and otherwise advantaged typically go unmarked here and the end of life narratives of people who lack access to those privileges are told in comparison to that unmarked ‘norm.’ This is an issue not only in this archive but also in much death studies literature in general, though there are authors who push back against this (e.g. Collective for Radical Death Studies, 2020; Moller, 2004, 2019).

### **3.1.6 Narratives of Social Needs at End of Life**

The sixth type of end of life narrative in these texts are those that center specifically on the social aspects of dying, for both patients and their loved ones. This particular aspect of a patient’s life circumstances is especially important in whether or not a person has a good or bad death. Many of these narratives focus specifically on the importance of spending meaningful time together at end of life. One reason comfort care and other forms of low medical intervention are portrayed as good is that, so long as the patient’s symptoms are adequately managed, there is opportunity for the family and loved ones to spend quality time together, thus providing opportunity for social roles to be fulfilled, social recognition to be maintained and, generally, for the person to die in a manner that is in keeping with their life.

For example, Friedrichsdorf (2015), the director of the center for pain management, palliative care and integrated medicine at a children’s hospital, tells the story of Ethan – a baby born with a congenital heart defect who suffered a major stroke while undergoing life-saving surgery at 10 days old. Ethan was left with limited brain function, his life sustained by a ventilator, without hope of recovery. Friedrichsdorf begins this article by stating outright, “Ethan Butler’s best chance to truly live was for his parents to accept the fact that their infant son would die.” He asked Ethan’s parents what, beyond a miracle, they hoped for in the situation. They responded that



they didn't want Ethan to suffer or to spend his entire life on the vent, and that, above all, they wanted him to be comfortable. Together, family and doctors decided to perform a 'compassionate extubation' and remove the vent from Ethan. They took him outside to see the sun for the first time and, to everyone's surprise, his breathing became regular and comfortable. The family was able to take him home two days later and spent the next several months with him before he died. As Friedrichsdorf puts it, "Ethan had as good a life, as long a life, as he possibly could have" and it is because his parents took the risk of taking him off the vent. They were able to treat him, generally, as they would a healthy baby – going to restaurants, the movies, boat rides and giving members of the family a chance to form memories with him – that would have been otherwise impossible if all their time and energy was put into curative treatment, managing the symptoms and side effects of life on a ventilator, hoping for a miracle. This way his parents and older sister were able to perform their roles as family members; his mother was able to live, for a short time, as Ethan's mother and to form memories of this time. While we do not have Ethan's perspective in any of this – which marks this narrative as different from the generalization that a passive patient typically results in a bad death – the author's and his interpretation of the parent's view is clear: Ethan had a short but good life and a good death in which his symptoms were managed and family was able to spend meaningful time with him, enacting their social roles.

As discussed in the Introduction, diagnosis often marks a moment of change in identity for the dying person. This change in identity impacts loved ones too. Hospice nurse Brown (2015, April) tells the story of an old Italian woman who kept trying to cook for and feed her dying husband, despite the fact that he could neither chew nor swallow and that ingesting food would, likely, make him feel worse. Food was her way of caring for and connecting with her family and, Brown speculated, "the last concrete gift she had to offer" her husband. Brown surmises that when

loved ones no longer need food it makes their dying more real to their loved ones.<sup>28</sup> It is thus as important for loved ones to accept an impending death and to adjust to their new roles – as caregiver and, to the extent possible in advance, as bereaved – as it is for the dying person. Brown ends the article by suggesting different ways that loved ones may be able to express care for dying people but it is not clear if she was able to help the woman in this narrative adjust to her new role in this way.

Social recognition also is an important element of a good death, though it is primarily referenced in passing in the narratives. Healthcare practitioners, especially hospice care workers, often come into their patients' lives at the end, but they want to be seen as individuals who have lived full and meaningful lives, not just as dying patients. For example, when Puri (2016) arrives to her first home visit of the day, Sergio has a photo album waiting to share with her: "‘I wanted to show you who I used to be,’ he tells me softly in Spanish. I barely recognize him in the photos." This desire is also expressed in the desire to die at home, with loved ones; a death that is 'in keeping' with who the patient is and was, is partly about being recognized as an individual and being able to live at end of life, to the extent possible, as yourself. As Gawande's (2014) research shows, dying people want to be able to continue to shape their life story, to live and be recognized even as they're dying (p. 146).

Loved ones and healthcare providers thus play important roles for patients at end of life. A recurring lesson in these narratives is that time and energy is often better spent being with loved ones – focusing on saying goodbye, closure, life completion and so on – than pursuing treatments that have a low chance of advancing the patient's goals or extending the amount of high-quality

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<sup>28</sup> I think Brown misreads the situation slightly, here; rather than seeing feeding dying loved ones as an act born of denial, I think these actions can be better understood as motivated by helplessness, by the need to continue to care for our loved ones but reflecting a lack of understanding of how to do so at end of life.

time they have remaining. This is true not only of the three narrative examples in this sixth section, but, as indicated by the previous paragraph, can also be mapped onto the rest of the narratives analyzed. All of these authors are healthcare practitioners and so, understandably, they have a primarily medical focus. However, the importance of social roles and social recognition at end of life is such that one has a hard time evaluating a death as good or bad without reference to them. While many of these narratives center on treatment decisions and patient agency in decision-making, the good death is also importantly about the dying person's positioning in light their social needs and roles.<sup>29</sup>

### **3.1.7 Bad versus Good Dying**

From these six types of end of life narratives we can infer the conceptualizations of bad versus good deaths operating within. Bad deaths are ugly, painful and full of unnecessary suffering, often resulting from futile or risky interventions. Prolonged dying is generally characterized as a bad death, as the patient's life is sustained without hope of recovery, often with negative side effects – physical, emotional and/or social – that may impact loved ones and caregivers as well. Additionally, deaths may be characterized as bad if the medical interventions leading up to death are not what the patient wants or if it is unknown what the patient wants. In general, bad deaths involve treatments that actively do harm, either physically as a result of side effects and recovery time, or socially and emotionally as in treatments that interfere with the dying person's ability to take up their dying role. Furthermore, stories of bad deaths frequently portray the dying person as

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<sup>29</sup> This may also partly explain why much of this work is undertaken by women. (See Order of the Good Death, as well.)

a passive recipient of treatment. Deaths of these sorts are told through narratives about high medical intervention and those in which patient's wishes are unknown or not followed.

Good deaths, on the other hand, are peaceful, often occurring at home, usually surrounded by loved ones and, insofar as the situation allows, in accord with the patient's wishes. In good deaths, the dying person is active, able to identify end of life goals or last wishes, and these are worked toward by both the dying person and their social networks. Ideally, it is these goals that guide treatment plans at end of life as well, rather than the 'default' goal of prolonging life at all costs. In those situations where it is not possible to follow the patient's wishes – because they are unknown or because the situation evolves such that their original wishes are no longer feasible or in the patient's best interest – a healthcare proxy, or in some cases medical team member, is able to make decisions in the best interest of the patient. Lastly, in good deaths the social needs of the dying person and their loved ones are met – everyone gets the appropriate social recognition, the dying person and their loved ones adjust to the patient's impending death and have time to say goodbye, to mourn or to just to be together. Good deaths are described in narratives of low medical intervention, in which patients define their own goals and in stories centering on the social needs of dying people and their loved ones. Indeed, the ideal death in these narratives is one following low intervention, in which medical uncertainty is managed as much as possible, the dying person is able to exert some control over their death and the social needs of patients, loved ones and caregivers are met.

As noted, this conceptualization of the good death generally aligns with academic literature on the ideal of the good death. It is not surprising, then, that this conceptualization perpetuates some of the biases in that literature, insofar as this ideal primarily pertains to people who die of terminal or chronic disease and further can secure adequate care at end of life. Under this ideal of

good dying, sudden, traumatic deaths are necessarily bad deaths. Furthermore, the risks of these sorts of deaths disproportionately impact poor people, Black people and other people of color. Additionally, people within these vulnerable populations are predisposed to the very conditions that typically result in long dying, however, as discussed by Puri (2016), many lack access to the necessities that increase the likelihood of achieving a good death. Lastly, the narratives within this archive are generally silent on the identities of the dying individuals and how each patient's unique positioning impacts their attempts to construct a good death. Which is to say, there may be perfectly sound rationales behind the choices made by the people in these narratives, but the judgments of the author-practitioners do not necessarily contextualize those choices when evaluating them as good or bad. All of which is to say that the good death constructed within this archive is cast in decidedly medical terms and discussed as though it applies to the U.S. population generally, when, in fact, it is constructed from the deaths of particular patients and addressed to particular audiences.

### **3.2 Part Two: Uncertainty in End of Life Narratives**

One of the important things to note throughout these narratives is that, almost exclusively, uncertainty is experienced by patients and/or their loved ones, as opposed to medical practitioners. Despite the necessarily uncertain nature of practicing medicine – of diagnosis, prognosis and anticipating treatment outcomes – doctors, nurses and other care providers are rarely shown grappling with this uncertainty in these end of life narratives. The narratives cover over these sources of uncertainty by focusing on the uncertainty inherent in medical decision-making, which is the most prominent source of uncertainty for dying people and loved ones. The types of decisions

faced by patients and loved ones seem to be constrained, generally, by the dichotomy of curative treatments versus comfort care; within each option there are then further choices between specific treatments or care strategies. In the narrative view, these choices should be made based on the fit between courses of treatment and the dying individual's life, goals and current medical situation. The ideal of patient autonomy dictates that it is the choice of the patient – or of their proxy if the patient is unable – yet it is medical team members that have access to and control over the information about the medical situation, treatment options, outcomes and so on (see Segal, 2000, p. 31). In the narratives, shared decision-making between these parties comes down to how patients/proxies act on the information and options presented to them, without discussion of that information itself.

The fundamental decision that patients face in these narratives is whether to approach their disease(s) via curative or comfort care – whether to privilege the future by sacrificing time now to curative treatment or whether to privilege now by managing symptoms with comfort care, without attempting to alter the course of the disease. Deciding between these approaches to treatment figures as one of the major events in almost every narrative; this act of decision-making moves the story along, while a delay in decision-making delays the progression of the plot. All medical decision-making, and especially those decisions made as a person is nearing end of life, is permeated with uncertainty. As the possibilities of gaining more time later – and more time at a tolerable quality of life – reduce, the more difficult the decision may become. Eventually, end of life decision-making inevitably comes down to the question of when to allow death to take its 'natural' course by stopping treatment. This puts additional pressure on end of life treatment choices. In other medical contexts patients or proxies may choose between different types of treatments but, ideally at least, treatment is stopped when the problem is fixed, or deemed

unfixable, rather than with the understanding that doing so will lead, more or less directly, to the end of the patient's life. It makes sense, then, that end of life decision-making would be portrayed as particularly important in pursuit of the good death, and central to these narratives, as the decisions of which treatments to undergo, which to forgo, when and why are made either in the attempt to prevent death or to shape the ending of a life into a meaningful experience for patients, loved ones and doctors.

Consistently, the authors of these narratives portray themselves and other healthcare practitioners as knowing which is the 'right' decision. A statistical view of dying weighs the probable outcomes and determines a course of action based on that. From there, the authors – writing with the advantage of hindsight – characterize a death as bad or good. What is not portrayed as uncertain in these stories is the medical knowledge that produced those possible courses of action and probable outcomes. From this view there is little room for discussion of what role medicine should play in end of life or how an individual case may impact medical knowledge. Furthermore, not acknowledging upfront the uncertainties inherent in medical treatment contributes to a lack of preparation for the unexpected, an unpreparedness for death itself.<sup>30</sup>

There are, however, two additional narratives that challenge this generalization, indicative of exceptions in narratives about end of life. First, Gawande (2014) tells of one of his patients, Jewel Douglass, whose goal was to be stable enough to attend her best friend's upcoming wedding. Unfortunately, an unforeseen development with her ovarian cancer prevents her from attending

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<sup>30</sup> It must be noted that there are a few narratives in which the author, and/or other medical team members within the story, show uncertainty regarding a particular case: Zitter (2015, Feb.) narrates uncertainty regarding whether or not she should continue to treat Vincent; Brown (2015, April) is uncertain whether to privilege the patient's wish to die at home above that of being pain free; Zitter (2015, Oct.) displays uncertainty over whether or not she should have given shared the poor prognosis with Michelle Moore's family after her recovery; in a brief narrative not overviewed in this chapter, Gawande (2014) is unable to answer the question of whether or not a particular patient is dying when asked by a member of the patient's family.

that wedding. Gawande met with Douglass upon her readmission to the hospital to discuss options. In light of the development of her medical situation, she was uncertain how to proceed. Douglass had fears about both what the disease would do as it progressed and about the possible side effects and range of anticipated outcomes of treatment options. There was the possibility of gaining more time with the surgery Gawande proposed, but there were also high risks of negative side effects. Eventually, after a discussion about what she hoped for and what, specifically, she feared about both the disease and the treatment, Gawande was able to translate Douglass' competing concerns into a medical plan which accounted for her aversion to taking risky chances but still offered her a chance at relief from escalating symptoms. Gawande did exploratory surgery but was unable to complete the procedure without taking what they had decided together were unnecessary risks. Douglass eventually enrolled in hospice care, was discharged from the hospital and was able to spend the last weeks of her life visiting with old friends and family members, which she described as her "lifeblood" (p. 242).

As part of the retelling of this narrative, Gawande comes to understand some of the difficulty of medical decision-making, especially at end of life in which people are weighing hopes against fears, trying to choose between possible, debilitating side effects and trying to gain as much high-quality time as possible. "The choice, I realized, was far more complicated than a risk calculation. For how do you weigh relief from nausea, and the chance of being able to eat again, against the possibilities of pain, of infections, of having to live with stooling into a bag?" (p. 236). Here, Gawande begins to understand what it is to approach end of life like a patient, rather than a doctor. In practice, the individual's view of the situation is much more complex than the statistical survival curve and the choice to sacrifice precious time now for the chance of gaining more time later – or to sacrifice later in favor of now – is fraught with uncertainty, with emotions,



hopes and fears, those of the dying person as well as those of any loved ones.<sup>31</sup> In the moment there is not always an obvious ‘right’ decision. Coming to appreciate the position of the patient at end of life allows Gawande to practice true shared decision-making, and come up with a plan that works for Jewel Douglass as an individual.

The second narrative that deviates from the portrayal of medical knowledge as certain in end of life narratives is told by Gross (2015), a hospice and palliative care physician. Despite knowing she will not make it out of the ICU alive, Gross’ patient, Ms. Weatherby, opts for what are typically considered invasive, life-sustaining treatments with the explicit purpose of prolonging her life as much as possible. Ms. Weatherby’s hopes are pinned not on cure or on staving off death for its own sake, but rather on trying to gain as much time as possible to help reunite her fractured family before she dies. She spends her final weeks working to bring her family together, conscious and intubated – an intervention which is generally considered so uncomfortable it requires sedation that “renders most people essentially unconscious.” The attending physician is confused about how intubation is considered palliative care but Gross pushes the issue, questioning whether there should be a stark difference between comfort and curative care. Ms. Weatherby has no doubts about her goals and is willing to undergo the medical treatments necessary to achieve them. Additionally, she was in a somewhat unique position to be able to communicate those wishes to her medical team directly, as a result of remaining conscious while intubated. Importantly, Ms. Weatherby defines a good death for herself and she accepts that she is dying. It may also be significant that her end of life goals were socially oriented; if she had other goals that drove her to extend her life as long as possible – earning a bit more money on the stock market or to cut a

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<sup>31</sup> Many patients will opt for treatments they do not want if they think a loved one wants them to do it (Gawande, 2014, p. 186).

disliked relative out of some inheritance, for example – her death may not have been characterized as unambiguously good. Overall, this narrative is the clearest demonstration that it is not just highly versus minimally invasive treatments that leads to the characterization of a death as bad or good but rather whether or not social needs are met. In this case, Ms. Weatherby is portrayed as meeting her own social needs, essentially through her own force of will.

Beyond this, though, the narrative of Ms. Weatherby is also about a patient challenging doctors' assumptions about acceptable quality of life. The medical-knowledge that produces possible courses of treatment and on which doctors rely to make recommendations is grounded, at least in part, on assumptions about the quality of life an individual may experience as diseases progress and/or after treatments. There are practical, as well as emotional, difficulties to those sorts of predictions and healthcare professionals are not insulated from cultural norms regarding evaluations of the worthiness and quality of life given particular embodied conditions (see Christakis, 1999; Timmermans, 1998). Not to mention that the lived experience of a disease or treatment varies with the individual and evidence suggests that what may seem unbearable in the hypothetical may not be in actuality (see for example Lulé, 2009). Ms. Weatherby defied the assumptions of her medical team by remaining conscious while intubated and by stating she wanted to be re-intubated if the circumstances arose. Indeed, Gross began the article acknowledging that practitioners should be willing to be affected by their patients: "The real test for physicians, then, is being willing to meet the challenge of discovering our patient's true wishes, the fulfillment of which may push us well outside our own professional comfort zone." Furthermore, within the narrative at least, Gross acts as Ms. Weatherby's champion, pushing other doctors on their assumptions. She states that this case challenged others', as well as her own, assumptions about what 'counts' as palliative care:

“I’m sorry? You’re telling me she wants to be re-intubated?” Ms. Weatherby’s attending physician exclaimed. “I’m not clear how this is palliative care? She’s never leaving the hospital.” When advanced life support becomes comfort care, where do we draw the line? Based upon what I learned from Ms. Weatherby, I would argue that palliative care begins by removing the line.

Ms. Weatherby defied her doctors’ expectations and, ultimately, impacted Gross’ understanding of medical practices. Based on her experiences with Ms. Weathersby, Gross suggests that the dichotomy between curative and comfort care should be broken down. Rather than focusing on the decision-making that leads to a good (or bad) death, Gross’ narrative focuses on medical practices and the role of the practitioner in delivering good care.

Ultimately, these two narratives teach us something about the roles of medical knowledge and the medical practitioner at end of life. In general, the narratives in my archive aim to change end of life care primarily by encouraging readers (as potential future patients and/or their loved ones) to recognize the statistical view of death, asking them to (prepare to) accept that they will die and be willing to recognize and cease futile care at the appropriate time. Some provide images of patients and loved ones able to merge the statistical and the individual views by recognizing and accepting end of life and responding such that the individual’s death was meaningful for patient and loved ones by fitting the patient’s life. As noted, though, none of this necessarily impacts the doctor’s approach to end of life. Gawande’s project and the narrative Gross provides of Ms. Weatherby are about the ways that medical practitioners can and should adjust how they approach the ending of a patient’s life, too. Gross openly questions some of the medical knowledge that shapes how doctors approach patients at end of life. She calls for a re-envisioning of end of life care, one acknowledging that curing and comfort may not necessarily be distinct. Gawande

calls for doctors to enter into actual deliberative encounters with patients at end of life, one in which both parties are offering information and deciding future courses of action together, in which both are active.

The argument within these two narratives is *not* one in which patients simply learn to make better decisions at end of life, which in most accounts is predicated on a more realistic outlook and in accepting death as a part of life, nor is it one in which practitioners simply learn to communicate better. Rather, the shift called for here is in how practitioners and medical institutions approach end of life and end of life decision making as a whole. By acknowledging medical uncertainty in the face of death – represented by Gawande’s realization that there is no clear, ‘right’ course of action and Gross’ willingness to say that doctors’ expectations of treatments and approaches to care in general may be fallible – these narratives challenge our assumptions about the roles of medical knowledge at end of life, of what ‘counts’ as relevant knowledge from which to approach dying and who has access to that knowledge.

Furthermore, in both cases the patient determines or alters not only the courses of treatment undertaken but the courses of treatment actually offered. Gawande and Jewel Douglass work together to come up with a plan that will, ideally, achieve the desired outcomes without being too risky – what Gawande calls a “palliative operation, an operation whose overriding priority [...] was to do only what was likely to make her feel better immediately” (p. 240). Ms. Weatherby requests what is typically considered curative treatment as her comfort care. Instead of practitioners coming to patients with predetermined treatment options, instead of medical knowledge setting the conditions of possibility for patient/proxy decision-making, in these two narratives the patient refigures the options for living at end of life. In these ways, these narratives

move us toward acknowledging the extent to which medical institutions and practitioners shape end of life, and good and bad dying.

In focusing on type of treatment, patient control over treatments or on broader social and structural issues at end of life, the majority of the narratives in this archive collectively build an image of the good death as one resulting from low medical intervention – with pain and symptoms managed to the best of caregivers’ abilities – and in which patient/proxy uncertainty is minimized, the patient is able to influence treatment choices and the social needs of patients and loved ones are met. This conceptualization of the good death is largely presented as a goal for patients/proxies and any loved ones to work toward. However, in covering over uncertainty on the part of medical practitioners and, in essence, pinning the possibility of a good death on individual moments of decision-making on the part of patient or proxy (decisions that are based on medical knowledge and advice given by practitioners), these narratives also cover over at least some of the difficulty of shaping a good death within contemporary medical institutions, as well as potential spaces of possibility between practitioners and patients/proxies to address those constraints.

Building from this conclusion, the next chapter considers some of the implications of this conceptualization of the good death and the role practitioners and medical institutions play in shaping end of life. In Chapter Three I read these same narratives from a different theoretical lens – that of choice versus care – in order to argue that the conclusions Gawande and Gross point us toward here may have a chance of actually changing care at end of life, precisely by shifting narrative attention away from decision-making at end of life.

#### 4.0 Chapter Three: The Logic of Care in End of Life Narratives

Building off the discursive shifts inaugurated by the mid-twentieth century death awareness movement, and working within a particular conceptualization of the good death that centers on the patient's (or proxy's) ability to make good decisions, the narratives presented in the *NYT* series 'The End' and in Gawande's *Being Mortal* are about the failures of contemporary medical institutions to shape good deaths. Even narratives of good deaths are presented as goals to work toward, rather than the expected norm. The blame for this failure is laid in different places, depending on the argument forwarded: medical institutions and insurance practices that push patients, proxies and practitioners toward particular types of treatments, doctors who aren't prepared to communicate about end of life, patients who haven't clearly communicated wishes or who are not ready to accept mortality, unequal access to resources and so on. The arguments for fixing these issues differ based on where blame is placed. However, the majority of the solutions offered come down to enabling patients to make better decisions – more informed, more practical, more fitting decisions – through advanced care planning, more effective practitioner communication, changing institutional priorities or insurance practices, shifting individual assumptions and expectations about mortality or end of life, and so on. In this chapter, I argue that the narrative focus on decision-making may actually be counterproductive to the goal of advocating for a well-timed death.

Following from my close reading of the narratives in Chapter Two – in which a good death is typically portrayed as dependent upon treatment decisions, the ability of the patient to influence those treatments and outcomes, as well as on the social positioning of patients and loved ones throughout the dying process – we can see that a good death is shaped by both the material

conditions under which a person dies and the perceived ‘fit’ between the ending and the rest of the person’s life. Which is to say, the good death is narratively constructed based on decisions that affect pain and symptom management, courses of treatment, where and when a person dies, who is present while the person is dying, who is in charge and so on, as well as from the perceived fit between those effects and the dying person’s roles, relationships, values, interests and overall life narrative. What I show in this chapter is that both the material conditions and the perceived narrative fit are shaped by the underlying logic through which end of life is approached and, importantly for our purposes, through which the narrative of that ending is articulated.

Adapting Annmarie Mol’s (2008) framework of the logic of choice versus the logic of care in medical practices, I argue that reading these narratives through the logic of care shows that what makes a good death possible is not necessarily the discrete decisions or actions of individual actors that are typically highlighted in practitioner narratives of end of life, as my analysis in Chapter Two demonstrated. Rather, I argue, good dying is facilitated by an enabling of care that allows the patient and their social networks to co-create a good death. While the deaths in my archive are overwhelmingly narrativized through the logic of choice – in which the autonomous patient, or their proxy, makes decisions based upon the (ideally) value-neutral information presented by healthcare providers, who then enact patient decisions – rereading them through care exposes the limits of choice at end of life: the logic of choice cannot account for the historical life of the dying person and can actually foreclose caring practices by cutting patients off from caring networks, preventing members of those networks from taking an active role in helping to end the dying person’s story. The perpetuation of the logic choice in end of life narratives perpetuates the risks of bad deaths and does not address the causes of the failures to create the conditions of possibility for good dying. Shifting the logic through which end of life is narrativized shifts the

conceptualization of the good death – one frame through which end of life is evaluated – thereby shifting standards of judgment for understanding the ending of a life.

This is not to say that there cannot be narratives of good deaths told from within the logic of choice – indeed, my analyses in Chapter Two counter that idea. But, as I discuss in more detail in Part One below, the narrativized logic of choice points us toward the wrong things in conceptualizing the good death. In particular, the logic of choice in end of life narratives covers over the necessity of other actors at end of life, especially the role of others in bringing the dying person’s life to a close. Ending the dying person’s story – helping to bring their life story to a coherent conclusion and facilitating or even taking on their responsibilities and projects – is a crucial element of the good death, as one of the goals is fit between the life of the individual and the way in which they die, including the timing of their death. People with chronic or terminal illnesses who are approaching end of life are increasingly dependent upon others, which means, among other things, their social and medical networks are crucial to their ability to take up the dying role, come to some kind of closure, endure the work of daily life and, generally, shape their dying. An ecological or networked view of agency, such as the one Mol gestures toward in articulating the logic of care,<sup>32</sup> considers not only the other human actors crucial to one’s living (and, in this case, dying), but also the various medical technology and devices, spatial, institutional and social arrangements, and discourses (and so on) that enable the completion of these tasks at end of life. I primarily use the term ‘network’ in a narrower sense in this chapter, to refer collectively to the loved ones, medical practitioners and any other human actors who share in the work of dying – primarily calling those ‘social’ or ‘medical’ networks.<sup>33</sup> There are also times,

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<sup>32</sup> Discussed in the next section.

<sup>33</sup> This is not intended as a strong distinction between the medical and the social, but rather to highlight different collectives dying people are embedded in.



though, when I refer to broader ‘care’ networks to label the various (human, non-human, ideological, discursive and material) arrangements that enable healthcare practices.

In what follows, I first discuss the logic of choice and the logic of care in more detail and consider, in particular, their role in end of life narratives. Perceptions of good dying are partly about the stories we are able to tell, and, when viewed through the logic of care, we see a different emphasis in the conceptualization of good dying. In Part Two, I turn to the narrativized logic of choice which perpetuates the ideology of the autonomous individual as decision-maker and typically renders the healthcare practitioner as narratively passive, before considering the narrativized logic of care, which directs attention to the necessary distribution of agency in caring practices – thus shifting the conceptualization of the good death and the resulting evaluations of end of life – in the last section.

#### **4.1 Part One: The Logic of Choice and the Logic of Care**

Mol’s (2008) project is about contrasting choice with care, rather than the more common contrast between choice and no choice or between choice and force. The logic of choice, under which the choice-no choice dichotomy falls, places responsibility for outcomes onto the patient-decider (pp. xi-xii), as in statements like “It’s his choice” in response to whether or not the patient wants to continue with the clinical trial or switch to hospice care (Byock, 2015). Mol argues that the logic of choice, which is predominant in healthcare institutions and is foundational in the West in general, is primarily concerned with autonomy. Individuals are called upon to make medical decisions based on information given them by healthcare providers. Within the institutional logic, communicative roles are assumed to be neatly divided: doctors, nurses and other healthcare

professionals present neutral facts, customer-citizens choose based on their values, goals and preferences and, finally, professionals implement those choices using treatments and medical technology as means to the patient's chosen end. However, this oversimplifies not only medical knowledge – mirroring my conclusions in Chapter Two regarding the narrative absence of uncertainty on the part of healthcare practitioners – but also presumes a direct relationship between treatment, as the means, and a patient's goals as the ends, eliding the possibility of unexpected or unintended effects. These effects are then considered 'complications,' rather than matter of course when dealing with unpredictable bodies. Furthermore, treatments are activated by the moment of choice; the moment of choice is presumed to occur before treatment begins, everything else follows from that choice, overlooking all the interventions in a patient's life (as well as those of any loved ones) before treatment 'officially' begins. Overall, Mol contends that the logic of choice does not translate well into healthcare settings, especially in cases of chronic illnesses like diabetes, which is the focus of her study, as living with a disease is a complex, necessarily uncertain and ongoing process.

In contrast, Mol articulates the logic of care which she sees at work in some doctoring practices. The logic of care takes caring for patients to be a process, beginning from a view of patients as embedded in collectives – which is to say, in various networks – and accounting for the varied, daily practices of life with chronic disease. Rather than privileging the moment of choice, in which a patient decides their goals and permits doctors to enact treatments to get them there, care is an ongoing process, not a bounded-transaction or a contract. The central question of a care-centered approach is 'Do the actions and reactions of the actors involved in caring fit with one another and work to better the patient's life?' Rather than a concern with who has the authority to make decisions, as articulated in concerns over patient autonomy, doctoring founded on the logic

of care enables different members of the care team – which, importantly, includes the patient themselves – to engage in caring practices as needed: “[T]he main emphasis is not on autonomy and the right to decide for oneself, but on daily life practices and the attempts to make these more livable through inventive doctoring” (p. 84). Additionally, good care recognizes that the facts of medicine are never value-free – and do not necessarily precede decision-making nor action – and especially not so when addressed to patients. It is not only pancreatic cancer in general that matters, but it is the cancerous growths within *this patient’s* pancreas, how that impacts their life, identities, relationships, future and so on. The relevant facts depend upon what can be done to better this particular patient’s life. By asking, “what can be achieved in practice?” (p. 51), the logic of care begins with the life of a specific patient, considers a range of possible parameters as goals, incorporates as many actors as necessary and encourages inventive doctoring in order to improve the patient’s life.

We can extend Mol’s discussion of logics in healthcare settings to consider the articulation of those logics in narrativizing healthcare situations. A logic “carries a whole world with it,” as Mol writes about the ideal of choice: “a specific mode of organizing action and interaction; of understanding bodies, people and daily life; of dealing with knowledge and technologies; of distinguishing between good and bad; and so on” (p. 7). We could add to this a particular mode of narrativizing: ways of discursively presenting action, actors, interactions, bodies, choices, etc. Within healthcare, the logic of choice shapes knowledge, perceptions of the body, relationships between people and between objects, actions, reactions, aesthetics, ethics, and so on, organizing them into the rational and irrational, the good and bad. The logic through which it is approached shapes how a medical situation is perceived, responded to and, importantly, talked about, which further impacts how future situations are perceived and responded to. Most of the practitioner

narratives about patient deaths reflect and perpetuate the logic of choice, thus reflecting, shaping and perpetuating particular standards for evaluating the good from the bad, the desirable death from the undesirable.

In addition, though, perceptions of good versus bad dying is also shaped by the narrative itself. The dying person co-constructs a good death with loved ones and healthcare practitioners while they are alive, however it is the surviving members of their social and medical networks who tell the story of the death – who reflect on, construct the meanings of, fit together into a cohesive whole, and so on – after the fact. And *how* these stories are told matter in perceptions of the death. For example, Brown’s (2015, Oct.) piece “Finding the Meaning of Death in the Concert Hall,” discussed in the previous chapter as an example of a narrative in which the patient is able to shape end of life treatment, makes this point quite clearly. Brown recounts the difficult death of one of her hospice patients, a memory that was “unresolved,” as she put it, one she hadn’t come to terms with; the patient wanted to die at home, however they were unable to control his symptoms and eventually decided to transfer him to the hospital. In the meantime, the patient was suffering through an ugly, painful death while they waited for an ambulance to navigate icy winter streets. The memory of this patient’s death is unresolved until Brown is able to reframe it by focusing *not* on the patient himself – his pain and suffering and her helplessness to alleviate it – but on the “feeling of love in the room” from the whole family, including the dog. Shifting her focus away from the dying individual, and the choices he made that she was not able to honor, and toward the family instead enabled Brown to tell a different story. Which is to say, focusing on the family as a whole, how they acted in his best interests to the best of their ability and maintained their familial relations throughout, rather than on the failure to honor the individual’s choice, allowed Brown to re-narrativize this death. Through this reframing after the fact, Brown shifts this story from being

a bad, unresolved death to an, at least, good enough death. Brown's ability to narratively de-center the patient is what allowed this to become a narrative of a good death. This retelling opens the possibility for understanding end of life otherwise and for shaping approaches to future end of life situations.

A good death is thus both about what happens in the time leading up to death and how the story is conceived of and told afterwards. The logic through which these stories are narrativized reflects both narrative decisions made by the doctor-author, as well as, presumably, the logic through which the medical situation itself was approached. Overall, as with many of the other narratives I analyze, Brown's narrative is told through the logic of choice, though she gestures toward the logic of care in expressing her dissatisfaction with the story she is initially able to tell through the ideal of choice. Even while narrativized through the logic of choice, many of the stories expose the limits of that logic and the risk of foreclosing care inherent within that approach.

It is part of my argument in this chapter that changes in how end of life is narrativized can impact our perceptions of end of life, as well as our standards of judgment with regard to death and dying, and of what it takes to create the conditions of possibility for good dying. Which is to say, if, as I argue in Chapter One, one of the collective goals of these narratives is to advocate for 'well-timed dying' – a good fit between the life and the death of the dying person, or, to state it with a slightly different focus, between the biological and social deaths of the dying person – narratives that can't account for the historical life of the person, that cut dying people off from the social networks that make up their social lives and that are responsible for the completing the dying person's narrative, won't help people achieve that end. Rereading these narratives through the lens of choice versus care shows a different version of the good death, one which accounts for both the material and the narrative conditions under which a person dies.

As we'll see in more detail below, end of life as narrativized through the logic of choice emphasizes elements similar to the ones Mol found in her direct observations of diabetes treatments and discourses: the patient as autonomous individual and decider, the moment of choice as the agential moment in medical practice, the healthcare practitioner as the one who dispenses (theoretically) value-free medical information, proposes possible plans of action – based on patient condition, wishes, values and so on – and enacts those wishes. In general, within the logic of choice, the good death looks like what I already discussed in Chapter Two. The dying person defines their own end of life wishes and, insofar as is possible, those wishes are followed, resulting in deaths that are in keeping with who the dying person was. The patient retains agency as long as they are able – and even longer with the help of advance care planning – and side effects and negative symptoms are minimized, ideally through the choice of comfort care (as opposed to highly invasive curative treatments), so that the social needs of the dying person and their loved ones can be met. In these narratives, the choice between low or high medical intervention – between curative and comfort care – is the decisive moment.

However, as noted in Chapter Two, the situation isn't always so simple. In addition to the people who are narrativized as having made 'bad' choices and end up with bad deaths as a result, or vice versa, there are some people who don't quite fit the neat breakdown between bad and good deaths – most often people who made the 'right' decisions but didn't have the anticipated outcomes or, on the other hand, people who made the 'wrong' choices to good outcomes. What we see in this dominant narrative vision, then, is an ideal of the good death that hinges on patients (or proxies) making the right decision at the right time in order to create space for a fitting and meaningful death. While there are exceptions, the majority of these stories effectively place responsibility for constructing a good death on the dying person themselves. Rereading these

narratives through the logic of care, however, gives us a view of good dying which is an ongoing process co-constructed by various actors, illuminating the extent to which the logic of choice more often functions as a barrier to good dying.

Narrativized from within the logic of care, good dying is about the end of the historical life of a person, about ending a person's story in such a way that fits with the rest of their lives and that their surviving loved ones, and healthcare team, understand it as a good death after the fact. When we talk about whether or not a person's death was in keeping with their life – whether or not their wishes were honored, whether or not they maintained their social roles and so on – what we are really talking about is the ending of the dying person's story. Which is to say, insofar as the self is an ongoing project in both the neoliberal, control society, self-governance sense (see Deleuze, 1992; Rose, 2007) and in the sense of the continual narrative construction of self (see Linde, 1993), then a person's death is of special importance as the ending of that project. Gawande reminds us that dying people want the chance to continue working on those projects, to continue to influence their story, even as they are faced with increasing dependence (p. 146). It is up to others in the dying person's social and medical networks, then, to facilitate that work and perhaps even to take it on when the dying person is no longer able.<sup>34</sup> Thus, the responsibility of ending the dying person's story falls upon both the dying person *and* the loved ones they leave behind.<sup>35</sup> The dying person and members of the person's care networks are jointly responsible for that ending as, at end of life, the dying person's projects – including their role in their own care – and their legacy

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<sup>34</sup> For a particularly striking example of this, see the story of Adam Warner whose wife, Meghan Baker, was diagnosed with breast cancer approximately one year after they began dating and died the following year, one month after they were married. Following her death, Adam took over Meghan's blog, where she had chronicled her experiences with breast cancer, as well as the list of goals she wanted to complete before she died. Adam writes "Because of Meghan and for Meghan I am finishing her list of goals. ... my underlying purpose through all of this is to complete what Meghan couldn't ... My hope is to tell her story and spread her message of love and inspiration..." (Warner, 2010).

<sup>35</sup> See also Lingis (2000) 'To Die With Others'

are increasingly distributed among their social and medical networks. What that distribution looks like differs on the logic on which treatments, doctoring and caring practices are founded, and through which the stories are narrativized. But agency at end of life is always networked.

When approached through the logic of care, the good death is not primarily dependent upon the specific choices an individual does or does not make. Rather, good dying is dependent upon the attunement of the dying person's care – including the actions of patient themselves, loved ones and practitioners, treatments, medical technologies, medicines and everything else that intervenes in and shapes the dying person's life – to the historical life of the dying person, and the attunements of those caring practices to each other. Reconsidering these narratives through Mol's framework of choice versus care reveals that what matters most in shaping the conditions of possibility for good dying is the enabling of caring practices that allow the dying person and their social or medical networks to co-construct a meaningful death in keeping with the dying person's life. Insofar as these narratives both reflect and shape how the good death is understood – that is how a death is evaluated – and how future patients and loved ones may approach end of life situations, the logic through which end of life narratives are told and are read is of particular importance.

Narratives that center primarily on individual decision-making and courses of treatment chosen don't seek to shift public discourse or understandings of the good death toward distributed agency in caring practices. Instead they perpetuate the myth of the autonomous individual in the face of death making the right decision at the right time in order to construct a meaningful death. End of life narratives told through the logic of choice perpetuate the idea that it is primarily up to the individual to align their biological and social deaths – the material conditions under which they die and the fit with their life story – whereas those told through the logic of care highlight that the



work of dying is shared and it is the coordinated actions of many actors within the broader caring network that enables good dying.

## **4.2 Part Two: Logic of Choice in End of Life Narratives**

Mol talks specifically about diabetes but calls for approaching other healthcare situations through the logic of care (pp. 90-91). Following this, I extend Mol's framework to consider the roles of the logic of choice and the logic of care in healthcare practitioner's narrativization of end of life and depictions of good versus bad deaths in particular. Here, I reconsider in detail four narratives from my archive that, generally, display the logic of choice approach to healthcare situations, in which the patient is the autonomous individual and decider, the moment of choice is the moment of agency and the practitioner is, typically, rendered narratively passive. Revisiting these narratives allows us to flesh out some of the implications of the constructions of the good death discussed in Chapter Two and provides an opportunity to consider how this conceptualization could be shifted and to what end. I consider the narrative constructions of patient, the act of decision-making and practitioners in turn, before turning to the narrativized logic of care in Part Three.

### **4.2.1 Patient as Autonomous Individual**

Within the logic of choice, the dying person is approached first and foremost as an autonomous individual who – barring any evidence to the contrary – is capable of rational decision-making with regard to their health. In the event that they are unable to actively decide at some

future point in time, the individual is still the decider, even if it is a matter of their proxy or other member of their social network being asked to guess what the patient ‘would have wanted;’ the ideal, though, is to have an advance directive that reduces future uncertainty by detailing the patient’s wishes. Advocacy for advance directives, and other advance care planning, is typically articulated through the logic of choice. In general, advance directives are an attempt to assert control over future situations in which one wouldn’t otherwise be able to exercise that control. Many have noted that advance directives should be treated more as conversation starters, a way for loved ones to have some idea of your values and what you as a patient would want in possible future circumstances. In either case, though, the patient is asked to consider in advance a general approach to future treatments based on their goals, values and/or wishes, fill out and make available the proper paperwork documenting these wishes or at least speak with loved ones and/or doctors about them. Zitter’s (2015, Feb.) narrative of Vincent – a “frequent flier” in Zitter’s ICU primarily because of his advance directive, which made absolutely clear that he wanted everything done to keep him alive as long as possible – narrativizes this autonomy and its potential impacts quite clearly.

The narrativized logic of choice emphasizes that courses of treatment are the individual’s choice. Despite no longer being “with us,” Vincent was approached, first and foremost, as an autonomous individual and, thus, primary decision-maker. As an autonomous individual, Vincent’s choices ten years prior in his advance directive became the guide for his treatment. Zitter observes that most advance directives from nursing homes are “cookie-cutter similar,” as Vincent’s was except for the handwritten note reiterating he wanted absolutely everything done to keep him alive. The majority of these directives state that they want all measures taken to prolong their lives. Advance directives are signed by two people, in these cases typically the admissions

clerk and social worker and “Almost never the physician,” Zitter states. In this way, Vincent’s situation potentially failed to meet even the ideals of the logic of choice, in which a doctor talks the patient through diagnoses, prognosis, treatment options and the patient’s goals and values, so that they can make an informed decision in keeping with their individual life. Additionally, advance directives should ideally be revisited regularly, and especially whenever one’s medical situation changes, to confirm that the directive still match the patient’s wishes. As noted, Vincent’s advance directive had not been updated in ten years. Zitter points out these shortcomings and, yet, Vincent’s choice, documented in the advance directive, guides his treatment.

At same time that the patient’s choice is emphasized, the agency of the practitioners is deemphasized. In Zitter’s narrative, the practitioners caring for Vincent seem to exist solely to enact the patient’s decisions and are not depicted as actors themselves. Vincent was admitted the first couple times for septic shock resulting from pneumonia caused by coughing food into his lungs. In order to address this recurrent issue, surgeons inserted a feeding tube into Vincent’s stomach, but that only made matters worse and did not actually solve the problem of food in his lungs. From that initial action by surgeons, Zitter writes, “More tubes sprouted,” seemingly of their own accord. The tubes “sprout” in response to the decisions Vincent made ten years ago, not in response to the decisions and actions of the practitioners actually inserting them. In the name of patient autonomy, then, Vincent became a carrier for various tubes – a stomach tube for feeding, a neck tube for breathing and a bladder tube to avoid urinary tract infections – and a host to antibiotic resistant bacteria. Narratively, Vincent’s relationship to his own body and the relations between him and his medical care team were produced by choices that Vincent himself made “a life time ago,” rather than by the actions and decisions of his care team.

The act of deciding a course of treatment – or, in this case, a general orientation to treatment (i.e. curative care) – is the agential moment in the narrativized logic of choice. Vincent’s situation causes Zitter to question medicine’s “blind faith” in patient autonomy. She instead considers that perhaps some patients *shouldn’t* be in charge of their own care, as she doesn’t imagine that Vincent could possibly have known what he was setting himself up for. In the narrative, though, there is no indication that the cause of Vincent’s ending could lie anywhere other than Vincent himself – even though by her own admission he probably didn’t know what he was really choosing – or in the medical institution’s conception of patient autonomy. Which is to say, Vincent suffered as he did either because he made a bad choice ten years earlier or because the medical institution privileged that choice. Either way, it was that choice that produced these results. That Vincent had a prolonged, gruesome death was narratively *not* the fault of the individual practitioners because they aren’t granted narrative agency. In questioning the ideal of patient autonomy, Zitter is gesturing beyond the logic of choice but does not seem to have an alternate framework through which to narratively construct her relationship to the patient. And so, either the patient (or proxy) chooses and doctors enact those choices or the practitioners choose for them. Either way, it is the act of decision-making that matters in end of life care.

To be clear, Vincent did not necessarily suffer a bad death because his treatment was approached through the logic of choice. Rather, as discussed in Chapter Two, it was a bad death because the specific choice(s) he *and* his healthcare providers made resulted in pain, a prolonged death and a series of futile treatments which isolated and dehumanized him, turning his physicians into “medical vending machines.” Narrativized through the logic of choice, fault lies with Vincent for making bad choices or with the medical institution for allowing him to make those decisions, eliding other possible sources of responsibility. The logic of choice does not invite readers to view

the situation otherwise. However, that his ending was not altered by anyone ostensibly caring for him, *was* a result of the logic of choice dominating the relationships between Vincent, his treatment, the medical institution, doctors, his nursing home and so on. Which is to say, Vincent's death is narrativized as it was because the logic of choice privileges the moment of choice as the moment of agency, while at the same time constraining what counts as a 'choice' and who is empowered to make them.

In the narrativization of the logic of choice the practitioner-patient relationships are constrained such that the practitioner is not able to fully take responsibility for the dying person. Within Zitter's narrative, Vincent, as an autonomous individual, is severed from potential networks of care – namely individuals and possible processes or procedures at both the nursing home and the hospital – by the inherent values of the logic of choice. If Vincent had someone in his life who was seen as capable of intervening on his behalf he may have been spared. Zitter puts it very simply: “there was no family, no friend, no person from Vincent's life to serve as a guide for our treatment goals.” Thus, Vincent was narratively “abandoned” – cut off from particular elements of his networks – and approached as a patient without an agentic network. However, Vincent lived in a nursing home just down the street from the hospital, presumably staffed with caregivers and social workers, yet there was no one in his life who could speak for him. His advance directive was witnessed by the admissions clerk and a social worker from the home, and still there was no one authorized to intervene on his behalf, who could make treatment decisions for him, either overruling or confirming his stated wishes. On his eight visits to the ICU before Zitter took over his case, Vincent was treated by practitioners who were oriented toward the task of his treatment by institutional structures and medical knowledge, granted authority to enact particular procedures and processes in pursuit of that goal, but none of whom were able to guide his treatment. So, while

Vincent was certainly embedded in networks of humans and bureaucratic procedures at the nursing home and the hospital, he was also isolated, cut off from these networks – or rather these individuals were constrained in their relations to him and thus he was approached first and foremost as an autonomous individual. While it is elided in the narrative, inherent in this is that he was approached *by* someone, by his healthcare providers and by the institutions that were caring for him, backed up by the various arrangements that make treatment possible, and who were making ongoing decisions about his treatment.

The logic of choice frames the relationships between patient and other human actors such that loved ones, as possible proxies or next of kin, are empowered to make decisions for the patient and healthcare providers or institutions are prevented from doing so, except in the most extreme circumstances. Agency at end of life is always distributed across networks, but practitioners are narratively – and presumably otherwise – constrained in their capacity to act for and with their patients. This is not to say that practitioners do not take responsibility for their patients. It is to say, though, that some members of a patient's networks *are* granted agency to act on their behalf (typically loved ones), while in other situations a patient is simply a node in more general processes that are merely interrupted or activated. Vincent's advanced directive and medical condition activated a certain set of procedures within Zitter's ICU – founded on the logic of choice – that led to disastrous results for Vincent and dehumanized the people treating him.

In sum, Vincent's narrative should not be read primarily as a case of medical intervention gone awry, though it certainly is also that. Rather, it should be understood as a case of individual autonomy gone awry. Zitter points us toward this failing by questioning the "blind faith in patient autonomy" but, as mentioned earlier, she does not seem to have an alternative framework through which to understand the role of the patient and the relationships between practitioner and patient.

Thus, Vincent is approached as an autonomous individual who simply lacks a network. But this shouldn't *necessarily* be an issue in the logic of choice, which intentionally approaches patients first and foremost as autonomous individuals. Even as end of life is narratively constructed through the logic of choice and even when the agency of any other actors is narratively erased, elements of the narratives themselves expose that the patient isn't, couldn't possibly be, the only or even the primary agent. The logic of choice is founded on an ideology of individual decision-making but always, more or less secretly, relies upon networks of actors assisting in healing, treating and dying.<sup>36</sup>

It is worth underscoring that end of life is a time of increasing dependence for most people. The image of the dying individual as primary decision-maker shaping their death in accord with their wishes, even if they are unable to directly communicate them, emphasizes autonomy, self-control and self-discipline in a context that necessarily exposes the fundamental limits of the ideal of the autonomous individual. This is one attempt to capture the ending of life from that dependence, from those limits. Within the logic of choice, the autonomous individual remains autonomous even in the face of death, in the face of increasing dependence and in situations where others have to decide what courses of action to take. Even in those situations where the patient *can* decide, they still require others to act on their behalf, to act with, within and for them. The limits of the ideal of the autonomous individual are exposed by the execution of those choices that necessarily call upon networked, rather than individual, action. Agency at end of life is always networked; the crisis comes with the narrative foreclosing of those networks and the failure to understand the dispersal of responsibility in bringing a person's life to a close.

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<sup>36</sup> Similarly, as Gil Eval (2013) argues, the expertise of doctors, and that of experts in other fields, is made possible by a range of 'background practices' and "the social, material, spatial, organizational, and conceptual arrangements that serve as its conditions of possibility" (p. 871).

In contrast to this narrative, it might be fruitful to briefly consider the story of Ms. Weatherby (Gross, 2015). As discussed in detail in Chapter Two, Ms. Weatherby knew she was never leaving the hospital but opted for life sustaining treatment as comfort care in order to gain more time to repair relationships within her family before she died. This death is narrativized as a good death and points palliative care specialist and author, Gross, to consider that curative treatments and comfort care shouldn't be treated as two distinct categories; in other words, she realizes that treatment can be caring. Ms. Weatherby is an ideal patient within the logic of choice because she knows exactly what she wants and is willing to do whatever it takes to get there. She is the idealized agentive patient, self-disciplined and self-controlled even as her body is increasingly out of her control; she is the center of her social network and narratively she maintains and directs those ties. She displays remarkable self-awareness in her ability to clarify and reiterate her wishes and, with help from Gross, determination in sticking with them in the face of push-back from conventional medical wisdom. However, this story is only narrativized as a good death because of her apparently singular personality and strength of will. Ms. Weatherby creates her own good death against the odds. It is only because she is able to defy the odds and expectations that Ms. Weatherby is able to make the most of the logic of choice and shapes a good death by extending her life to continue her work herself. This narrative demonstrates the faultiness of the ideal of choice at end of life: most will not be so lucky as Ms. Weatherby. Even this good death, largely narrativized through the logic of choice, points the author away from that logic and the neat division of the choice between curative treatments and comfort care, in particular.



#### 4.2.2 Moment of Choice as Agentive Moment

As seen in Vincent's narrative, in the narrativization of medical practices it is the decision, the moment of choice, that activates and authorizes all the actions that come after. Treatment thus cannot begin until after the patient or their proxy reaches a decision about how to proceed. Even when the decision-making of practitioners is narrativized, their agency is narratively erased and they are not portrayed as decision-makers. In 'The I.C.U. is not a Pause Button,' McConnell (2015), an ICU nurse, recounts the experiences of caring for an unnamed elderly man who was weak and unwell, not "rising to the challenge to consciousness and physical independence," primarily due to a lack of oxygen. The patient and ICU team are awaiting a decision from the patient's proxy about whether to change his status to 'do not resuscitate / do no intubate' but the family is unable to decide. The patient had been on a ventilator but it was removed once his condition became stable. However, his oxygen levels did not improve, so the ICU team switched him to continuous positive airway pressure (CPAP), which pushes oxygen into the lungs through a mask. The CPAP is not designed for an unconscious patient who is unable to pull the mask off as needed, however. If, for example, he vomited with the mask on, the CPAP would push the vomit into his lungs along with air. The ICU team were avoiding using the CPAP because it didn't fit his specific situation but he wasn't getting enough oxygen on his own. In this case, the patient's nurses and doctors are making a range of decisions about his care, however those decisions are not articulated as *decisions* in logic of choice-based narratives. The logic of choice privileges some choices over others – the decision to continue life support and/or curative treatment or to transition to comfort care, in particular – which covers over the fact that many decisions are being made all the time in support of patient's lives and deaths.

The idea that medical treatment ‘pauses’ to await one particular decision from patient (or proxy) stems from a view of treatment as a bounded transaction that occurs in response to moments of choice and that understands the choice between curative treatment and comfort measures as a strong bifurcation. As stated, the patient’s family knows of his condition and is waiting to decide what to do. According to McConnell, they seem to view the situation as being ‘on pause,’ which, she points out, of course it is not:

The patient was living through these hours and days, mask on, mask off, a feeding tube in his nose, IVs in his arms, having his dry mouth sponged, his throat suctioned, defecating and being cleaned up. He was alive, and while he wasn’t in pain, he wasn’t passing the time pleasantly.

While narratively erased, his care team is actively making decisions and enacting these life support treatments and daily care. Despite this, because *the* end of life decision (when to stop treatment) has not happened yet, the situation is registered ideologically – and narratively – as ‘nothing happening,’ by those not present at least.

Furthermore, the actions and reactions of the patient in response to and as active partners in their treatment are narratively erased by the primacy of the moment of choice as well. The narrativized logic of choice does not account for the body of the patient as agentive in the broader network. Even in this case, while the patient is unresponsive, his body is still active and reacting to treatment. On some level, he is an active as well as a passive part of the treatments. It is worth quoting McConnell at length on this point:

It is harder to believe in this pause button when you witness the constant poking and suctioning, the invasive examining and monitoring, the parade of medications and the contraptions necessary to deliver them, the lights and alarms, the coughing and grimacing

and shuddering – or, in the less responsive, the bloating and stiffening or slackening and eventually the eerie dehumanization of both the patient and the caregiver. Thinking that intensive care can pause the march of time is a misunderstanding or willful fantasy. There are always bargains to be made and discomforts to be faced in a place that is staving off death.

Witnessing these medical practices, it is impossible to believe that treatment, and life support in particular, is a bounded transaction. Healthcare providers are continually acting on their patients and patients are continually acting and reacting in response to their embodied conditions, to treatments and to the impact treatments have on their lives and beings. Even unresponsive patients respond to those treatments as healthcare providers act within and on them, and the monitors, lights and alarms react to and mediate the patient's responses. In the absence of a specific order from patient, proxy or doctor to limit treatment, this process "will continue indefinitely, regardless of the anticipated outcome in quality of life." Additionally, according to McConnell's narrative at least, the family seems to believe that their responsibilities are limited to choosing a course of treatment. The humanity of everyone involved is eventually subordinated to the pursuit of prolonging a life. Patient and healthcare providers are dehumanized but the machines continue unphased, while the family deliberates over their (perceived) one moment of action. In this way, medical interventions intervene in not only our bodies, but also who we are and in our humanity, in our being in the world.

The monitors and machines that represent the status of the patient are relied upon to tell us whether or not the choice – or the default of prolonging life in situations where we act as though a decision has not yet been reached – is being honored. As others have noted, in the ICU in particular, a patient is often approached first and foremost through the range machines which monitor and

support vital functions (see Butler, 2013, p. 79). It is the readings on the monitors that guide the care a patient receives; the living person can fade into the background. McConnell calls attention to this through an anecdote of an interaction with another nurse: “Another nurse walking by put it bluntly, as nurses tend to do. “Is he alive?” Of course he was alive. We could both see the safe numbers and steady weaves marching across the monitor.” According to the information available on their monitors, both nurses can clearly see that the patient is alive, but that sense of ‘alive’ means something different; that isn’t what this question is about. The physical body represented on the screens and monitors is living in a technical sense but the lived, historical life of the patient – into which treatments also intervene and which is of major importance in the course of ending that life – cannot be accurately represented. Healthcare providers are bound to those representations and the meanings of their actions are bound to that as well.

This is one reason, following Mol, our issues with end of life care cannot be fixed from within the logic of choice. Choice cannot account for the historical life of the person, and furthermore, the logic of choice constrains the networks of care the person is in, as well as understandings of what constitutes treatment and so on. The reduction of ‘aliveness’ to representations on monitors prevents practices that care for the whole person. Privileging that ‘aliveness’ constrains a patient’s caring networks.

The final point to take away from this narrative is to reiterate that oftentimes practitioners are prevented from taking on a more caring role, even when they want to, by institutional commitment to the logic of choice. Within the ICU, and other medical institutions, the ends are largely set: prolong life. This is one reason the narrative bifurcation of the choice between curative and comfort treatment is so strong. At end of life, living longer will eventually be out of reach and so those parameters should be revisited. In cases where the patient is unresponsive, a proxy is

tasked with deciding what the goals should be. It is clear in McConnell's narrative that she believes prolonging life should no longer be the goal in this case, but she doesn't have a choice in the matter:

Doctors, nurses and technicians care about our patients, but sometimes we cannot express our care by doing what we think is best for them. In the I.C.U., that is not our job. Our job is to preserve life.

In the absence of a particular choice from patient or proxy, the decisions that McConnell, and others, can make are constrained by pre-established parameters. With choice as the ideal, and the specific choice between prolonging life or not as the most important of those choices, practitioners are unable to care, in Mol's sense, which forecloses the patient from doctoring based on the logic of care. The risks of a bad death are multiplied by the magnification of one particular choice, made by a dying person or their proxy, likely in a moment of crisis.

#### **4.2.3 Healthcare Practitioner as Passive Actor**

As seen from the previous analyses, healthcare practitioners are typically narratively erased or portrayed as passive. The patient is the autonomous decider and the primary roles of the practitioner are to provide information, counsel the patient/proxy if necessary or if requested, and enact treatments in accord with patient wishes or goals. As these narratives are told from the point of view of the practitioner-author, we do read more of the doctors', nurses' or specialists' motivations, thought processes and the obstacles they face in treating people at end of life: Zitter's horror at Vincent's condition, Gross acting as a champion defending Ms. Weatherby's choices, McConnell's frustration with her ICU patient's family and the institutional barriers that prevent her from doing what she thinks is best, and so on. While these behind-the-scenes images of

healthcare practitioners are good, these stories still center on patient choice and, by and large, the role of the practitioner is narratively constrained by those choices. Given the tendency to narratively construct practitioners as agentively passive, in some ways it is easiest to see the narrative norms for practitioners by considering those stories where they push against those limits.

One such example is the practitioner who goes above and beyond in their responsibility to the patient, typically to shape a patient's decision in accord with what the practitioner thinks is right given the medical situation. A prime example of this is the story of an unnamed 29-year-old told by Gawande (2014, pp.185-87), who was told this patient's story from the oncologist who treated the patient for inoperable brain tumors. The patient eventually opted for hospice, rather than pursuing a third type of chemotherapy after the first two had failed. The initial conversation between the patient and the oncologist to make this decision took more than an hour, though, as the patient expected to continue curative treatment. Then the oncologist met with the patient and his family all together and, a few days later, individually with the patient's father at his home to discuss the list of experimental trials and treatments he had found on the internet. She patiently went through each one with him and explained why they were not a good fit for his son's condition. "The oncologist noted wryly how much easier it would have been for her just to prescribe the chemotherapy" (pp. 186-187), Gawande writes, but instead she was able to convince the family that the patient's life was ending, that more treatment would likely make him worse and that, in her opinion, the best course of action was to privilege their remaining time together rather than continue to fight for the unlikely chance of more time in the future. The patient opted for hospice and, as discussed in the previous chapter the family ended up grateful for the opportunity to spend his last month together without the demands of curative treatment in the way.

While exhibiting caring practices, this narrative is still primarily told through the logic of choice. The oncologist is clearly narratively active and, importantly, considers not only the opinions and wishes of the patient but also the impacts of his loved one's opinions and wishes on his decision-making; however, the focus remains on the patient's decision. All of this activity and communication is ancillary to the act of deciding, which contributes to their devaluing. The oncologist goes above and beyond her duty to the patient in her attempts to convince him and his family that he was making a mistake. Importantly, the oncologist did not force him to decide one way or another, did not say she would not treat him, but wanted to help him make a truly informed decision by being frank about his condition, the treatments she had to offer and what she saw as the best course of action. The primary point Gawande draws from this narrative is how much time and energy it requires from practitioners in order for patients to make well-informed decisions. Again, the issue is narratively constructed as the patient's decision-making process (ill- versus well-informed), practitioner communication practices (whether or not the practitioner is willing to be frank and to go the extra mile) and/or institutional procedures that shape the outcomes of these decisions (i.e. that make it "easier... just to prescribe the chemotherapy"). The emphasis remains on the ideal of patient decision-making and what institutions and practitioners can and should do in support of that.

In addition, stories like this demonstrate that the primary issue with which the logic of choice is concerned – autonomy or who has control – isn't even adequately addressed by the logic of choice. Doctors actively and passively influence, direct and, at times, even manipulate patient decisions. In treating the doctor as an expert who is bound to the patients who consume their services, the doctor is in the position to decide how much of what types of knowledge to disclose, despite the patient being the one ostensibly 'in charge.'

Narrated through the logic of care, we thus see practitioners constrained in their ability to assist patients at end of life. We see practitioners attempting to persuade patients and loved ones to choose in particular ways, as in the example above, or we see practitioners following the patient's lead and offering what they think the patient wants. Gawande gives us an example of this in his conversations with an oncologist at his hospital, Dr. Marcoux, who treated Sara Monopoli (pp. 149-52). Monopoli was 34 years old and pregnant with her first child when doctors discovered she had advanced, non-small cell lung cancer. A few days after inducing labor and delivering a baby girl, Monopoli, her husband Rich and her parents met with Dr. Marcoux to discuss options. He proposed chemotherapy options and explained that, for some patients with similar conditions "responses [to the treatments] can be long-term" (Dr. Marcoux, qtd in Gawande, 2014, p. 151). According to Gawande, "it seemed harsh and pointless to confront" them with the fact that lung cancer is terminal and the median survival time is about a year – i.e. for Dr. Marcoux to clarify what he meant by 'respond' and 'long-term.' Monopoli went through three rounds of chemo which had minimal impact on the course of her disease. Even at this point, a few months later, Dr. Marcoux stated that the 'signal' he got from the family was to continue considering treatment options: "They did not want to talk about dying" (p. 165). Thus, Monopoli ended up pursuing a fourth round of chemo, "And it all happened because of an assuredly normal circumstance," writes Gawande, "a patient and family unready to confront the reality of her disease" (p. 167). According to conversations Gawande had with Rich after Sara died, while they knew there was no cure for her disease and Sara said she did not want to die in the hospital on multiple occasions, they never discussed ceasing curative treatment (pp. 165-66). Practitioners are continually making decisions about how to communicate with patients and loved ones, how much of what types of information to give and how to frame it. In this narrative, Dr. Marcoux followed the lead of patient and family,



leaving them unprepared for the inevitable. Which is to say, Gawande narratively seems to place responsibility for their preparedness on the family, without directly attributing it to the choices that Dr. Marcoux himself made in discussing prognosis or treatment options.

A logic of care approach within these narratives would enable us to discuss with more clarity how practitioners shape end of life treatments and choices, as active participants in framing medical knowledge and creating the conditions of possibility in which decision-making, as well as other medical action occurs. Narratively presenting practitioners as (to the extent they are able) neutral providers of information and passive enactors of treatment centers responsibility on the patient as decision-maker, rather than asking readers to consider how Dr. Marcoux, for example, contributed to their unpreparedness because of his narrative role as the provider of medical information. Focusing on the practitioner as an active, agentic member of the patient's caring network would encourage readers to consider that possible plans of actions – the possible options that patients are to choose between – are not set and to acknowledge the role healthcare practitioners play in shaping end of life wishes, decisions and the conditions of possibility for good dying. It would also enable us to see more clearly that doctors, nurses and other practitioners are actors who require support and care themselves.

One thing that is important to acknowledge here is that the decision of when to cease curative treatment *is* a bifurcation point in end of life decision-making, treatment and narratives. This decision of general approach to treatment is about the parameters the caring network should be reaching toward – generally speaking, toward the attempt to prolong life, privileging the future, or toward attempts to make a person's life more comfortable, privileging now. The discussion of parameters is important in any healthcare situation, though, as discussed in Chapter Two, this decision at end of life is particularly fraught. However, as we saw in Gawande's story about Ms.

Douglass and Gross' (2015) narrative of Ms. Weatherby in Chapter Two, the strong division between cure and comfort – which is upheld narratively, in medical knowledge and by institutional and insurance care silos – may limit options at end of life. Furthermore, it may also constrain caring practices by limiting parameters to two, distinct options (cure or comfort) and shape what those look like, what treatments and practices are or can be involved.

To be clear, the division between the logic of choice and the logic of care should not be conflated with one between life-prolongation or hospice/palliative care. Instead, the logic of choice presupposes a narrative in which the cogency of individual choice is the best way to understand and evaluate the bad or the good death. Thus, medical practitioners offer the individual actor the choice between curative treatment options or the choice to cease curative care. The logic of care insists that there is not a cogent, individual narrative to be had there, as agency at end of life is networked and it is the attunement of action across that network that helps shape the conditions of possibility for good dying. Within narratives told through the logic of choice, the patient is given a choice between attempting to live longer or not; practitioners shape when that choice is offered and what practices those choices entail, despite narratively constructing that choice as the responsibility of the patient. It is something of a false choice though. When faced with terminal or life limiting illnesses, inevitably the goal of living longer will eventually be out of reach; a patient's choice may have nothing to do with it. As we'll see in the next section, narratives told through the logic of care begin with the embodied condition of the dying person and, to the extent possible, account for the historical life of the person and ask what can be done, by which actors, to improve this person's life, however long that may be.

### 4.3 Logic of Care in End of Life Narratives

There is only one narrative in my archive that seems to be narrated through the logic of care: the story Friedrichsdorf (2015), a physician at a pediatric hospital in Minnesota, tells of Ethan Butler's death. Ethan suffered from a congenital heart defect and a rare complication from surgery ten days after he was born resulted in a stroke, required him to be on a ventilator and left him subject to seizures, with limited brain function. There were no available curative treatments; Ethan was expected to live the rest of his life on the vent. Friedrichsdorf and his team from the department of pain medicine, palliative care and integrative medicine were invited in to meet with Ethan's family.

Within the narrativized logic of care, medical practitioners approach patient and their loved ones as active members of the patient's caring network. Friedrichsdorf and the palliative care team ask the family "Just in case the miracle does not happen, what else are you hoping for?" Rather than presenting the prognosis and asking what the family wants to do, the palliative care team in this narrative assert their active roles in his care, ask how they can help and what are the next steps they can take together, rather than delivering bad news and laying out treatment options. By tabling hope for a miracle to begin with, the medical team positions themselves as part of Ethan's care network and on the same side as the family. They do not dismiss the desire for a miracle – indeed by bringing it up, it seems they share it – but suggest that there may be more to be done to improve Ethan's life than wait for one.

It is worth noting here that Gross asks a similar question of Ms. Weatherby and her other hospice patients: "If I had a magic wand, what would you wish for today?" These types of open-ended questions – that, importantly, don't center on medical treatment while still creating space for patients to discuss treatment issues if they wish – narratively give patients and/or loved ones

space to consider their concrete goals and wishes in that moment. This allows the care team, including the patient, to assess and, hopefully, address the patient's needs, positioning them to actively improve the life of the patient.

Choices are still a part of narratives told through the logic of care but the moment of choice is not the only moment or even the primary moment of action. This narrative hinges on a decision, as with many narratives told through the logic of choice, however it is a decision that the family and the medical team make together in order to give Ethan the best life possible. The family responds to Friedrichsdorf's question that they don't want Ethan to spend his entire life on the vent. As a result of this decision, Ethan's familial and medical networks come up with and enact a plan for him to live as long and as well as possible. They remove the vent, manage his symptoms and take him outside in an attempt to facilitate good dying: to let Ethan see the sun for the first time and die outside with his family around him. Unexpectedly, Ethan survives. His breathing stabilizes and he is able to go home a few days later. The initial decision to remove the vent enables the rest of the narrative but it is *not* the only moment of action in the narrative: doctors act to ease Ethan's symptoms, palliative care staff members make home visits, the family learns to care for Ethan, form memories with him and so on.

Even after leaving the hospital, Ethan is still narratively embedded in social *and* medical networks of care, as the palliative care team visits the home daily at first, and then less frequently over time as the family is increasingly able to care for him on their own. The palliative care team supports Ethan and his family, teaching them how to care for him physically but also encouraging them to treat him "like any other baby." In this way, the palliative care team and his family are actively engaged in Ethan's care and they are all actively responsible for his life and its ending.

Narrativized through the logic of care, the necessity of ending the dying person's story comes to the foreground. As discussed in Chapter Two, this narrative emphasizes the importance of the family creating memories with Ethan, of living out their roles as Ethan's mother, father, sister and family while they are able. Additionally, his family, and his mother in particular, are well attuned to his physical condition and possibly able to sense that his death was nearing, giving opportunity to facilitate the good dying they hoped for: "He was looking a little gray and they had a feeling the end was near. By the [water]falls, under the sun in his mother's arms, Ethan looked up into her eyes and took his last breath." Ethan's medical and social networks are thus responsible not only for caring for Ethan at the end of his life, seeing to his day to day needs, but they are also responsible for his legacy, for ending his story by forming memories with him that they themselves carry into the future and which become part of their own life stories.

That this narrative is about an infant, a patient who is too young to have a fully developed sense of self or agency, is telling. Ethan's care is, by necessity, already understood to be networked and the narrative can emphasize those networks because there isn't an autonomous, agentic patient to be the decision-maker. Ethan is incompatible with the logic of choice; even more so than an incompetent or incapacitated adult, because he doesn't have motives to speculate on or a fully formed identity beyond that which is projected onto him. Read through the logic of choice on the one hand, this simplifies the question of 'who is in charge' because there is one less (agentive) actor. Through the logic of care, on the other hand, we see that Ethan's age forces proxies, loved ones and healthcare practitioners to stop acting as though the patient is fully autonomous; we literally cannot imagine that his network could *not* be activated by his condition or involved in his care.

To be clear, I am not saying that Ethan is the ideal patient within the logic of care, nor that we should treat dying people like infants or narratively infantilize them. I am saying, though, that it is not a coincidence that the one narrative in my archive that is told primarily through the logic of care features an infant. Ethan's social positioning and his (lack of) agency means that he falls outside the logic of choice and, thus, responsibility for his care and for ending his life falls directly on his caring networks. It is Ethan's social positioning and his agency that allows the doctor-author to narrate this death through the logic of care, in which care is an ongoing process, the work of which is distributed across social and medical networks, and the primary question is "what can be done in practice to better this person's life?" Ethan's narrative is instructive because it shows how dying could be narrativized.

This narrative also emphasizes loved ones and medical practitioners, who will typically take on an increased role in any end of life situation. Ethan was too young for us to get his perspective. But we never get a final perspective from any dying person (see Lingis, 2000) and, statistically at least, the majority of dying people will lose the ability to make decisions and act as agents of their own care in the process of dying. From the perspective of the dying person, if they are aware they are dying, good dying is about the time they live as a dying person, their imagined ending and the imagined futures of the people they leave behind. To loved ones and healthcare practitioners, good dying is about that and also the actual ending of the dying person – the time after the patient loses consciousness, the moment of death, the memories they carry about the person's death and of their life. Ending the dying person's story becomes an element of the loved one's story; the dying person's projects – their hopes, fears, wishes, plans and responsibilities – and their legacy are extended and diffused across their networks. Ethan shows us this quite clearly by being something off an outlier. The death of this 4-month-old child is narrativized as a good

death because his family shared the responsibility for his life, identity and projects. He lived as their son and brother; they formed memories with him; they cared for him physically and socially. This narrative enables us to see them clearly as his legacy.

Thus, we can see that end of life as narrativized through the logic of care would shift conceptualization of the good death to emphasize the historical life of the patient and the caring practices distributed across the patient's caring networks that work to improve the dying person's life and bring their story to a close. Good dying, in the logic of care, is facilitated by the attunement of those various practices with one another and with the life of the person. The logic of choice, on the other hand, narrativizes the good death as the result of individual decision-making and, in this focus on the autonomous individual, can actually foreclose caring practices by narratively cutting dying people off from their caring networks, which are crucial in the work of dying.

Following Mol, the logic on which end of life treatments, doctoring and narratives are founded shape how a person dies in practice and, from the present analysis, the perceived fit between their life and their death, insofar as that logic and the stories that are told from a particular death shape how a death is perceived. Insofar as the narrativized logic of choice does not easily account for the historical life of the person – in reducing the moment of agency to a single choice which cannot possibly reflect that historical life – and approaches the dying person first and foremost as an autonomous individual – responsible for their own self-knowledge and self-control – the issues articulated as the medicalization, professionalization and denial of death, and through concerns over the timing of a person's death, cannot be addressed adequately nor broadly through the logic of choice.

As these narratives are all told for persuasive affect, to enact some type of change in how end of life is conceived of and approached, part of the underlying argument of this chapter, and

indeed the whole dissertation, is that how dying and end of life are narratively characterized has some impact on public discourse at least, as well as possibly individual beliefs and actions. Which is to say, a renewal of thinking with regard to possibilities at end of life is possible through careful attention to how these narratives arrive at their conclusions. These narratives contribute to standards of judgment with regard to death and dying, reflecting and shaping expectations, desires and conceptualizations of what is possible and desirable at end of life. When read through the logic of care, they point us toward a reconceptualization of the ways medicine is conceived of, practiced and institutionally organized.



## 5.0 Conclusion

In the *NYT* op-ed, ‘Dying Shouldn’t be so Brutal’ (2015) – discussed in Chapter Two – Ira Byock, palliative care physician and author of the now classic *Dying Well* (1997), briefly recounts his experiences with a dying friend, Michael, who must choose between hospice care and experimental treatment as part of a Phase I clinical trial. Byock laments the policy and institutional structures that prevent people from dying in the ways they wish, that fail to facilitate comfort, well-being and dignity for dying patients, stating that what we have is “brink-of-death care” not end of life care. “Dying is not easy,” Byock writes, “but it needn’t be this hard.”

Byock’s article is part of an archive of contemporary discourses that collectively advocate for acceptance of death through arguing for well-timed dying or, stated another way, against unwanted and/or futile prolongation of life, which often results in ugly and painful deaths. The ideal of the good death – the idea that the physical effects of dying can be mitigated; psychological, emotional, relational and/or economic impacts can be managed; and, ideally, the dying process can be meaningful for a dying person and their loved ones – animates this advocacy. Generally speaking, these contemporary discourses extend the arguments of previous movements for death awareness in their articulations of the issues of medicalization and denial of death, though they are responding to the contemporary medical, technological, social and discursive contexts. Within the contemporary practitioner narratives that make up my archive, the good death follows from low medical intervention chosen at the *kairotic* moment by the patient (or proxy) and is one in which patient/proxy uncertainty is managed, the patient retains decision-making ability as long as possible and the social needs of patient and loved ones are met. This version of the good death that emerges from these narratives generally aligns with contemporary literature on the good death,

reflecting the rise of a hospice and palliative care approach to end of life overall, which, again, is a legacy of the earlier death awareness movement.

While this is not necessarily problematic in itself as an ideal to work toward, these narratives reinforce the myth of the autonomous individual decision-maker and, in essence, leave the responsibility of shaping a good death to the decision-making of patient and/or proxy. The narratives I analyzed here are attempts to facilitate better decision-making in pursuit of good deaths, however in their general reliance on the individual as decision-maker – that is, insofar as they are narrativized through the logic of choice – they perpetuate the risk of bad deaths by not acknowledging the necessarily distributed nature of the work of dying. In directing attention to the dying individual as agent and the moment of choice as the agentive moment, good deaths narrativized through the logic of choice run the risk of failing to account for the full work of ending a life – including medical and daily care aspects, as well as the work of ending the dying person’s story – and the necessarily distributed nature of that work.

It is worth underscoring that these narratives are something of a shift from what came before. As I cover in Chapter One, while the death awareness movement did, in some senses, bring end of life to public discourse in new ways, it had limited impacts on the medical situations in which people actually died. Similarly, contemporary advocacy for death acceptance may be bringing renewed awareness of death, dying and end of life issues to more people, and it may be moving people toward accepting that they, and everyone they know, will die. And, insofar as death acceptance discourses generally advocate for at least skepticism, if not outright rejection, of the ‘conveyor belt’ of treatment at end of life, they may be moving people toward recognizing that there comes a time to stop striving for a cure or to beat the odds. As such, they may be developing new narratives for letting go, as opposed to fighting death until the end. There are small gains here.

However, in reproducing the neoliberal, control society ideal of the autonomous individual, in centering the dying individual as the primary, or even sometimes only, agent that matters in a story, in reducing the primary work of dying to choosing between treatment options and/or between comfort and care, and hinging a good death upon making the right decisions at the right moments, these narratives don't necessarily guide future patients or their loved ones toward achieving good deaths. There is no such thing as the right decision, except in hindsight, and given the necessary distribution of agency at end of life, there is no coherent narrative to be told about the *individual* who made the right decisions, enacted the right treatments and shaped a good death as a result. The decisions a person makes are always made in conjunction with others, the actions a person takes are always predicated on a host of background practices and arrangements that make action possible – in end of life situations, primarily the medical practitioners who frame the conditions of possibility for that decision-making; medical knowledge and institutions that generally make up the situations in which decision-making occurs; any loved ones who take on the responsibilities of caring for dying people and ending their life stories, and so on. A dying person can make all the 'right' decisions and end up dying a painful, drawn out death because dying is inherently uncertain and out of anyone's control.

The logic of choice, through which these narratives are overwhelmingly narrativized, cannot adequately account for the work of dying. As an example, according to research published at the end of 2019, for the first time since the early twentieth century, in 2017 more people died at home than in hospitals (Cross & Warraich, 2019, Dec. 12). Older, white men and, across the board, people with cancer were the most likely groups to die at home or, in the case of cancer patients, on hospice. However, as Cross and Warraich (2019, Dec. 11) and others (see Kolata, 2019) report, honoring the decision to move the site of care to the home does not necessarily lead to a good

death. It runs the risk of inadequate pain and symptom management and in many cases places a heavy caregiving burden on loved ones, the full scope of which may be unforeseen. While changing the site of dying to more closely align with patient wishes is not a bad thing, if that shift does not also address the systemic and structural, as well as narrative, issues that perpetuate the risks of bad deaths, then it only shifts these issues to a new site. Discourses that perpetuate the idea that the good death follows from the choice of low intervention at the right time and, generally, making decisions in line with one's values overstate our ability to control dying and place undue responsibility on dying people. As the good death is one lens through which people understand death and dying, a shift away from the logic of choice in end of life narratives and away from the autonomous decision-maker would enable us to discuss, conceptualize and evaluate the goals at end of life differently.

In Chapter Three, I propose the narrativized logic of care as one way of recasting end of life. The narrativized logic of care, for example, can shift us away from aiming for the ideal of the good death – or the individual ‘a good death’ – instead focusing on good *dying*, shifting standards of judgment by extending end of life from its conceptualization as a singular moment to a process that is shaped by various practices undertaken by various actors, including the dying person, over time and which are attuned to the goal of making a dying person's life more bearable, insofar as that is possible. These narratives would center on bringing the biological and historical lives of the person to an end and the distribution of caring practices across the patient's caring networks in pursuit of those goals. While there are certainly moments of caring within institutions, interactions and narratives founded on the logic of choice, the two logics themselves are incompatible, necessitating a broader shift toward the logic of care in order to address issues at the heart of the logic of choice within healthcare settings.

Stories that center on distributed responsibility, agency and caring practices in support of the project of ending a dying person's life won't fix our healthcare system. As this project focuses on the level of the narrative – on how stories of dying are told – I don't necessarily have answers for how a shift away from the logic of choice in actual doctoring practices or in medical institutions would be possible, nor what that might look like within institutional settings. However, taking seriously the idea that public narratives surrounding healthcare situations in general, and end of life in particular, can shape how past, present and future medical situations are understood, acted upon and judged, a general shift away from the narrativized logic of choice may enable people to see different elements of the situation, may enable practitioners to see their roles differently, may enable loved ones to have different conversations and for all stakeholders to work toward different goals. End of life narratives, as a type of illness narrative, are a form of epideictic rhetoric and, as such, reflect, reinforce and influence our collective values. Careful attention to the concept of the good death and how it is conceived of within end of life narratives reveals not only how we do approach and conceive of death and dying, as well as how we might organize around the fact of our mortality otherwise, but also our highest collective values. A shift in the rhetoric of dying might also shift interactions with medical institutions, judgments about end of life and our identities as (future) dying people and their loved ones.

Dying is a necessarily uncertain and out of human control. We can do things to mitigate the physical impacts, to extend or shorten the length of a dying person's life, to try to shape the economic, social, psychological and emotional impacts of dying, and so on, but it is still inherently uncertain and uncontrollable. And yet, we all still have to act in the face of death. Decisions must be made about what the goals should be, how we might get there and what potential barriers may arise in a dying person's life. Presenting medical information as certain, as the majority of these

narratives do, is one response to this inherent uncertainty; it is an attempt to set the conditions of possibility within which choices must be made, to limit the total uncertainty, in the best of cases, in the hopes that patients and their loved ones may be able to act. However, as I stated in Chapter Two, practitioners who don't acknowledge the uncertainty inherent in their own professional knowledge or in practicing medicine within human bodies likely contribute to patient unpreparedness for the 'unexpected.' Accounting for the *certainty* of unintended consequences and, furthermore, the extent to which any course of treatment impacts one's life and way of being as much as it impacts a person physically, is another possible response to acting in the face of uncertainty. Which is to say, acknowledging that there is not necessarily a correct decision may not make acting in the face of uncertainty any easier, but it may relieve some of the pressure.

The narratives I analyzed here are told by medical practitioners and, as such, also implicitly reflect the institutional logic in which these narratives played out. Narratives told by people in other positions would emphasize different aspects of end of life and may even construct a slightly different conceptualization of the good death,<sup>37</sup> but, as the logic of choice is a foundational ideology in American society broadly, I would be surprised if the majority of end of life narratives were *not* narrativized through the ideal of choice. That is one possible avenue for future research: How do dying people themselves frame end of life in contemporary public discourse? What types of stories do people tell about their loved ones' deaths? Additionally, several of the practitioners who authored the *NYT* articles in this archive have gone on to publish more recent books on end of life. It may be interesting to consider how the end of life narratives compare across media, as

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<sup>37</sup> See for example Meier et al. (2016) on differences in conceptualizations of the good death among dying people, loved ones and healthcare providers.

there is simply more space in a book than in an op-ed to develop ‘characters,’ comment on decision-making processes, the contexts in which those decisions occur and so on.

Furthermore, it must be acknowledged here that the focus of this study is necessarily limited by my choice of texts. These texts represent discourses that have circulated through one dominant public, though, generally, they present the versions of dying they cover – and the ideal of the good death – as largely a-contextual. In following this particular set of discourses, I am, in many senses, perpetuating the oversight that most death studies work is guilty of: an over-emphasis on middle class, largely white people who die of cancer or other terminal or chronic illnesses. Even those narratives that call attention to this generalization (e.g. Crosby, 2015; Ouyang, 2016; Puri, 2016) do so, generally, by lamenting that the deaths of the people in the narrative fall short of this ideal; which is to say, even as they draw attention to the fact that the ways people die are culturally-bound and reproduce inequalities experienced in life, they still prop up the discourses that circulate in support of this overarching system.

One of my goals in providing a snapshot of these discourses was to understand the extent to which they differ from what came before. This broader contemporary discourse in support of death acceptance claims to be working against a perceived taboo surrounding death, dying and end of life issues and, generally speaking, positions itself as a break from the status quo. When beginning this project, I wondered in what ways they deviated and in what ways they reproduced that status quo. The answer is that, while breaking some barriers and shifting the discourse in some ways, as noted earlier in this conclusion, these texts also generally reproduce the hierarchies and power structures surrounding end of life, even when they are calling attention to them.

There are thus several blind spots within this archive and therefore the conclusions I draw in this work. First, the narratives that make up this broader discourse tend to focus primarily on

those who die ‘too late’ – articulated in the concern over futile or unwanted medical treatment and prolonged dying – as opposed to those who die ‘too soon.’ This focus leaves out the people who die in accidental or traumatic ways, which includes the third most common cause of death according to the CDC (2017) – unintentional injuries – as well as all deaths from gun violence, suicide, drug overdoses, State-sponsored violence and so on. The version of the good death constructed within these texts is incompatible with deaths of these types, leaving a large portion of people out of the conversation and, possibly, contributing to unpreparedness for these sudden, unexpected deaths.

Second, as mentioned in Chapter Two, by and large these narratives leave out much information that may help to contextualize a particular patient’s approach to and decision-making at end of life. With a few exceptions, the positionalities of the people in the narratives are not explicitly identified, instead the narratives, conclusions and conceptualizations of the good death constructed and perpetuated within are presented as acontextual. This archival silence does little to further discussions about what actual people who live and die in the particularities of their individual lives might want or need at end of life, nor prompt readers to think about how their own end of life plans, wishes or goals – as well as those of loved ones’ – are shaped by their positionality. For example, what are the specific considerations for LGBTQ+ people at end of life? How might especially vulnerable populations approach end of life and what particular kinds of care might they need? Might people of different races or ethnicities, classes, religions and so on have different end of life goals not adequately reflected in the good death conceptualized here?<sup>38</sup>

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<sup>38</sup> See Acquaviva’s (2017) *LGBTQ-Inclusive Hospice and Palliative Care*, Moller’s (2004; 2019) *Dancing with Broken Bones* (2004) and *Dying at the Margins* (2019), as well as the archives of The Collective for Radical Death Studies (2020) for studies that do take these and other particularities into account.



The overall point here is that death and dying are culturally-bound, as is caring. The concept of the good death portrayed within these narratives comes from a medical perspective. On the most basic level, this means that the deaths narrated within are those of people who have access to medical care and who die with enough forewarning that they have the opportunity to discuss end of life with their healthcare providers and make end of life decisions. There are too many who are not so lucky and who, largely, are overlooked within death studies and in these national conversations surrounding end of life issues. In focusing on these particular discourses, I too contribute to this reproduction. It is a necessary next step to compare, for example, the speculations on the logic of care at end of life within this work with the narratives about end of life for poor people in the inner-city that are the focus of David Wendell Moller's (2004; 2019) work. The narratives Moller shares in these works about the particular challenges of dying while poor and the particularities of caring for poor people at end of life would no doubt enrich, complicate and challenge the more general conclusions I attempt to draw here. More work focusing explicitly on the narrativization of the good death for marginalized, vulnerable and/or oppressed people – and especially those authored by people within those communities – is a much-needed update to the death studies canon,<sup>39</sup> as well as contemporary discourses surrounding the good death, one which would help provide a fuller sense of the range of standards of judgment for evaluating a death and contribute to the project of facilitating better dying and coping with death for more people.

In 'Contesting Death, Speaking of Dying,' Segal (2000) noted a bifurcation between the ways dying is discussed in mainstream public discourse, where it is largely constructed as a human experience, and how it is discussed in hospitals, where it is a biomedical construction and, largely, considered a failure. I think that these two discourses have at least begun to merge over the fifteen

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<sup>39</sup> The Collective for Radical Death Studies (2020) is compiling just such an update.

years between that article's publication and when these narratives were published. The narratives in this archive are representative of a medical viewpoint and still generally cast dying as a human experience. Some of them comment on the need to bring the human experience of death back into medical institutions (for example see Warraich, 2015), but many seem to understand that dying is already a human experience, even within medical institutions. On the whole, these narratives are part of the attempt to account for the human within the biomedical, through encouraging patients to make the best choices in the context of their own lives in response to medical information. It seems that death itself is no longer necessarily a failure within these narratives. The concern is not that medicine cannot make people immortal, but that people continue to fail to die well, that institutions fail to facilitate good deaths.

In addition to this failure, the author-practitioners of these narratives are also reacting to their institutional context more broadly. Patient autonomy movements have fought hard for the right to be fully informed of diagnosis and prognosis, even when terminal, for the right to informed consent for treatment and the right to refuse treatments, among other things. The idea of patient autonomy and the protection of patient agency have been hard won gains in response to both atrocious and mundane wielding of institutional power. However, as Gawande (2014), Zitter (2015, Feb.) and others note, the shift from a more paternalistic style of medicine toward one that attempts to facilitate more patient autonomy hasn't necessarily granted patients actual agency, nor necessarily resulted in good deaths. Zitter asserts this has transformed doctors into "medical vending machines" who dispense medical treatment at customers' request, but also notes elsewhere that the option *not* to treat is rarely offered (see for example 2015, Oct.). Similarly, Gawande (2014) concludes that while decision-making was easy for patients under the old, 'Dr. Knows-Best,' paternalistic system – because there weren't any real decisions to be made – under

this ‘Dr. Informative’ model, patient decision-making is still constrained by the pressure to treat (p. 220). The embrace of the logic of choice within healthcare settings is clearly a response to this and the author-practitioners can be read as attempting to carve out more space for their patients to make actual decisions, that fit with who they are as actual people.

The attempt to carve out space for dying people to exert some measure of control and have a say in how the rest of their lives proceed within this institutional situation where patients, historically, don’t have much real agency and in the contemporary moment only have limited agency, is admirable. And especially so when that advocacy necessitates some amount of ceding of medical practitioners’ power. However, as I’ve stressed here, overreliance on the logic of choice puts further pressure on patients to make the right choice in a situation where they only have access to the medical knowledge that is shared and framed by practitioners and in a moment when who they are – or will be soon – is possibly radically different than who they have known themselves to be previously. Furthermore, as indicated in Chapters Two and Three, in many of these narratives the practitioner-authors want their patients to make the *right* choice, which is another way of saying they want them to make a *particular* choice, typically to switch to hospice or other minimally invasive treatment options at the proper time. All of which is to say that there are alternative logics on which to found that agency, ones which fit healthcare situations and end of life in particular better.

The concept of the good death affects how we prepare for end of life in advance, how we live through dying and the narratives that are told after the fact. All of that is shaped by the logic on which the conceptualization is founded. The ideal of choice cannot account for the uncertainty and lack of control inherent in dying, nor the loss of agency that comes with dying. The perpetuation of the logic of choice within end of life discourses does not prepare us for the work

of dying. Founded on the logic of care, good dying is about ending a person's story as much as it is anything else. End of life narratives founded on a logic that attempts to attend to the lived experience and history of the patient, keep the patient embedded within their social and medical networks, direct attention to the distribution of responsibility, agency and care across those networks and acknowledge the prevalence of unintended consequences is already well positioned to account for the loss of control and acting in the face of mounting uncertainty that those who face long dying will almost certainly encounter.

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