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**“That’s what hospice is supposed to do”: How U.S. hospice
care staff bridge philosophy and institutions**

Morgan Leff

2022 Anthropology Honors Thesis

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Glossary

Activities of Daily Living (ADL): ADLs are a measure of self-efficacy in routine self-care activities, such as feeding and hygiene.

Certified Nursing Assistant (CNA): A healthcare professional certified to give daily nursing care to patients under the supervision of a registered nurse.

Fall Risk: A term used frequently in medical facilities to describe physically disabled people who are in danger of falling, especially the elderly.

Long-Term Care (LTC): A name for medical care for the elderly or those with chronic diseases that occur over an extended period. Often used in the context of “long-term care facilities,” which was used as a catch-all term for nursing homes, assisted living facilities, and other residential institutions where patients might receive hospice.

Introduction

The hospice patient's uncontrollable screams had been ringing out through the nursing facility during all waking hours, the nurse reported. The hospice care team, seated along the office meeting room table, were all in agreement that urgent action was crucial. A more thorough sedation regime would be the best way to ensure the patient's comfort through her final days. But family dynamics would complicate the process of carrying out this plan of care. The patient had not designated a power of attorney, leaving her sister and husband to juggle the responsibilities of medical decision-making. Her sister had expressed support for further sedation, but the patient's husband resisted the change. The nurse reporting the case made a point to mention that the husband suffered from dementia himself. She insisted that the husband was "in denial," reportedly telling him "You want her to scream all day, and that's not comfortable for her. And that's what hospice is supposed to do, provide comfort." The nurse's understanding of end-of-life care views the denial of death and refusal to align with hospice's model of pain reduction as a selfish act by caregivers. The clinical coordinator suggested that the nurse, a social worker, and the chaplain stage a meeting with the family to convince the husband. The chaplain hoped that appealing to their Catholic background would allow her to offer spiritual guidance on the caring nature of increasing the patient's medication. Part of the hospice staff's care paradigm involves bringing the hospice model of pain alleviation in agreement with the worldview of caregivers. As a result, caregivers would ideally be able to see their actions in hospice as good care, fulfilling their obligations to their kin.

As much as the purely physical death may be universally human, the social and experiential dimensions of death are diverse and richly colored throughout history. In a *Social*

History of Dying, Allan Kellehear traces where, when, and with whom death occurred from the Stone Age to the Cosmopolitan Age. As urbanization progressed, dying became an increasingly private affair, confined to closed-off locations (private residences or institutions) and a shrinking circle of kin and professionals (Kellehear 2007). Simultaneously, the question of what constitutes dying has moved from criteria observed by communities or individuals to definitions upheld by professional institutions and governments (Kellehear 2007). Through the first half of the twentieth century, a demographic transition marked by increased life expectancy and a declining fertility rate made death an increasingly rare and abstract event for most people in the United States (Laderman 2003). Death was redefined as a medical event between the 1870s and 1920s with the development and proliferation of medical thought (Laderman 2003). Not everyone bought into these new understandings of death—for decades, the American Catholic Church fervently resisted the secularization of death (Nytrøe 2013). Regardless, the frameworks through which people experienced death and dying increasingly entered the domain of medical professionals, funeral directors, and the state (Nytrøe 2013). Death as a medical event is deeply tied to the mechanist ontology that locates dying within the individual body as a result of disease processes (Banerjee 2008). In a biomedical project that looks to dominate nature, death is “positioned as an enemy to be systematically sought out and destroyed” through aggressive medical treatment (Banerjee 2008, 26). However, in recent decades hospice movements have pushed back against the imperative to fight death on purely biomedical terms.

In the United States, hospice has become a common part of the dying experience for all but the most acute deaths. Patients are encouraged to enter hospice when two conditions are met: their prognosis is six months or less, and they no longer wish to pursue further curative treatment. Both Medicare and Medicaid—and most private medical insurance plans—cover the

entire cost of hospice services for qualifying patients. At the time of their deaths, half of Medicare recipients were enrolled in hospice services in 2018 (National Hospice and Palliative Care Organization 2020). The most common primary diagnoses of hospice patients were cancer, cardiovascular disease, and dementia (National Hospice and Palliative Care Organization 2020). Due largely to the nature of Medicare coverage, the vast majority (98.2 percent) of hospice services were “routine home care” occurring in a private residence or long-term care (LTC) facility rather than a dedicated hospice institution (National Hospice and Palliative Care Organization 2020). This professional care is primarily delivered by healthcare professionals, with the help of chaplains and social workers. However, these services rely heavily on external caregivers for much of day-to-day care through the staff of LTC facilities, privately hired care workers, or—most commonly—informal familial caregivers. As hospice dying becomes an increasing reality of life in the United States, we find ourselves grappling with how the ideals, costs, and challenges of hospice care play out in the current healthcare system.

My fieldwork took place at Amicus Hospice, a mid-sized private hospice with locations spread across the midwestern United States. Though the hospice team solicited patients from nearby health facilities, Amicus was not formally associated with any inpatient care center. Instead, Amicus provided “hospice-in-place,” where staff and any necessary medical equipment would be brought to the patient’s residence. The branch office where I resided was located in a city center at the border of two states, serving a radius that spanned urban, suburban, and some rural populations. Nationally, White patients make up a disproportionate portion of those utilizing hospice services (82% of Medicare hospice patients versus 74.8% of total Medicare recipients) (National Hospice and Palliative Care Organization 2020; The Kaiser Family Foundation 2020). Black patients, in particular, experience lower rates of hospice enrollment

(and higher rates of disenrollment), even when controlling for neighborhood socioeconomic status, education, marital status, hospice-level variation, religiosity, and many other factors (Cohen 2008; Rizzuto and Aldridge 2017). However, Amicus' patient population was split fairly evenly between Black and White patients, with a smaller cohort of Hispanic, Asian, and other ethnic minorities (reflecting the racial makeup of the city). The service area covers the city itself and all of the adjacent counties, as well as a number of counties in the neighboring state. While the majority of patients are Medicare recipients, Amicus provides hospice care regardless of ability to pay. As a result, the patient population is quite socioeconomically diverse, ranging from privately-insured wealthy suburbanites to uninsured or undocumented patients.

While a patient enrolled in hospice at Amicus, they received a variety of services including medical, spiritual, and emotional care. Hospice nurses visited patients weekly at their residences to provide comfort care, while also managing their medications. The social worker met with the patient and their family to help with caretaker arrangements, funeral home designation, and connections with outside services. The chaplain provided spiritual support for those who requested it, while the bereavement coordinator offered grief care following the patient's death. Amicus made an effort to personalize care when possible, arranging special services for birthday gifts, holidays, or veterans. Volunteers gathered books for a patient who liked to read and a radio for a blind patient who complained of boredom in their nursing home. In the final stages of dying, Amicus provided more intensive daily care to ensure a smooth transition.

My research primarily focuses on the experiences, perspectives, and decision-making of the Amicus hospice staff. The office where I did my fieldwork served a relatively small group of staff. The permanent fixtures in the office were the clinical coordinator, the secretary, and the

bereavement coordinator. Two social workers, a chaplain, two physicians, a marketer, several volunteers, and various nursing care staff moved in and out of the office on a daily basis. My motivation for emphasizing staff in my research was partly a logistical decision. My fieldwork took place during the summer, fall, and winter of 2021, while the COVID-19 pandemic raged on. Visiting hospice residences would have presented an unnecessary risk to very vulnerable patients and was often outright prohibited. However, hospice staff are of particular scholarly interest to me. They are uniquely positioned as mediators between hospice philosophies of care and the interests of biomedical institutions. Through my ethnography and analysis, I identify how an ethic of care arises from these tensions.

During most of my time in the Amicus office, I took on the role of a volunteer. This allowed me to regularly interact with nursing and office staff as I assisted with supply distribution or occasional errands. My other primary role was as a bereavement volunteer, where I handled both medical records and grief care for the bereaved families, friends, and partners of patients. My ethnography is pulled from my observations of Amicus' daily landscape and personal interactions with hospice staff. I also completed several extended one-on-one interviews with key interlocutors in the office. However, my most extensive data came from my observations of the interdisciplinary group "IDG" meetings. These meetings occurred every other Thursday morning, with most of the patient care staff gathering around a long conference table in the office (with a few virtual participants projected onto a nearby screen). The group would work through the list of enrolled patients one by one, moving first through admissions, then current patients, and finally reviewing the recent deaths. At a minimum, each care team consisted of a social worker, nurse, and chaplain. As we read through the list, each member would give a report about the patient's care, with input from the bereavement coordinator or

physician as necessary. This whole-team approach opened a window into hospice's purview over the patient's spiritual, social, and medical life. The IDG meetings also gave me the chance to observe the dynamics of team decision-making to uncover the ethics of care being deployed. The final contributions to my research came from a variety of online resources, printed handouts, and virtual conferences about Amicus, hospice care, and "deathcare" movements more broadly.

In a letter to the Canadian Senate, Saunders wrote that "the dignity and worth of each individual patient [are] central to Hospice philosophy (Saunders and Clark 2002, 371)." From its earliest days, the hospice movement has concerned itself with "[preserving] patient dignity"—an idea that is closely tied to the anthropological concept of personhood (Saunders and Clark 2002). Personhood is most centrally concerned with meaningful categorization of the person through social roles, juridical rights, and moral responsibilities (Buchbinder 2011). In the particularly liminal spaces of life, personhood is highly subject to biopolitical structures bridging the physical condition and social meaning (Svendsen et al. 2018). In the United States, Western understandings of the "person" presuppose the ability to act and imagine oneself as independent from the collective experience, both physically (as a separate body) and cognitively (in emotion, judgment, and agency) (Scheper-Hughes and Lock 1987). Locating the person in the body-self—where it is bounded by the lifespan—makes the liminal spaces of illness, birth, and death particularly precarious sites of personhood (Buchbinder 2011).

In Western cultural contexts, extensive literature attention has recorded how aging and dying can cause the degradation of personhood (Ballenger 2006). An obsession with aging "successfully" can implicitly sideline those who fail to live up to North American ideals of independence, productivity, and permanent personhood (Lamb 2017). For example, dementia patients might be imagined as "not fully alive, or even not fully human (Woods 1999)."

Biomedicine is often a reductionist space, where the body-as-machine paradigm privileges the objectification of the physical condition over the embodied experience or social personhood (Koksvik 2016; Leder 1984). Care for the ill, dying, and/or elderly then becomes a site for negotiating personhood, as healthcare workers navigate the conflicts between biomedical aging paradigms and social embodiment (Perry and O'Connor 2002). In a Danish context, Svendsen et. al recognizes the role of “temporal imaginaries” in caring for the personhood in a neonatal intensive care unit, an animal model research laboratory, and a dementia nursing home, where imagining the future builds the moral world of care in the present (2018). I argue that hospice often evokes similar temporal imaginaries of suffering as justification for comfort care, while also hopefully imagining the possibilities of a “good death” through which personhood is restored.

The first section of this thesis covers the construction of a “hospice philosophy” rooted in the history of the movement. In particular, I examine the ways hospice’s contrast to an image of “unfeeling” biomedical institutions plays out in the care decisions of Amicus staff. Section two dives into the way staff negotiate contested authorities of place while out in the field. Delivering hospice within patient residences can be a way of restoring personhood at the end of life but can also open up possibilities for ‘bad’—or even burdensome—death. The third section reflects on my own experiences volunteering with grief care, especially as they relate to the question of whom hospice care is ‘for.’ With this thesis, I will examine how Amicus staff build an ethic of care from the tension between idealistic hospice philosophies and the biomedical structures of contemporary U.S. hospice. The institutional structures meant to design and ensure a ‘good death’ (while protecting the interests of the state) can fracture care of the dying. As hospice staff

work within and around these structures, they build meaning in care strategies that restore personhood and engage a social understanding of death.

Section 1: Hospice Defines Itself

“Comfort, sympathy, empathy”

“What do you think are the most important goals of Hospice care at the end of life?” I asked Taylor, one of the nurse case managers at Amicus.

She hesitated for a moment to think, then spoke with a deliberate emphasis on each word she listed: “Comfort, sympathy, empathy.” The nurse explained, “It’s all about...being there for the entire team. And I say ‘team’ in that it could be four sisters for a brother, it could be a mom, dad for their child.” She expressed that, in hospice, communication is more than just a tool for gathering health information, but a method of care in itself. “The listening ear is so important because you listen to the family, and you have to pick up on what that family member is saying but not saying. That family member could be reaching out because they’re at their wits’ end, and they just need to talk with you. And then you could bring in the chaplain, social worker—I mean we have all of this right there, ready.” She went on to list the wide array of resources that hospice could procure: medical equipment, daily care supplies, social work, or nursing care. “If it’s something that we can get and it’s within reason or—and then, Medicare has a lot of control over what you can and cannot do. But the things that we can do, we’re going to do.”

As in the introductory vignette, Amicus staff justified their care decisions by explaining “that’s what hospice is supposed to do.” They overtly evoked hospice as a “philosophy,” distinct from other biomedical modes of care. The Amicus Hospice volunteer manual lays out the following tenets in its opening pages, which it asserts to be shared by the National Hospice Organization:

1. Death is a natural part of the life cycle. Hospice intervention will neither seek to hurry death nor postpone it.

2. Pain relief and symptom management are appropriate clinical goals.
3. Psychological and spiritual pains are as significant as physical pain, [and] addressing all three requires the skills and approach of an interdisciplinary team.
4. Patients, their families, and their loved ones are the unit of care.

In accordance with these ideals, good care for the dying takes on medical, social, experiential, and temporal dimensions. As Taylor attests, the manifestations of hospice philosophy are found in care through “comfort, sympathy, empathy.” Amicus Hospice offers “comfort” in both the relief of physical suffering and by resisting processes that degrade patient personhood at the end of life. “Sympathy” evokes an expectation of emotional care that spawns grief, spirituality, and kinship. “Empathy” speaks to the centrality of relationships between hospice staff and those who receive hospice care. Yet, despite these lofty humanistic ideals, hospice philosophy strains under the demands of rapid expansion and institutionalization. As Taylor points out quite frankly, “Medicare has a lot of control over what you can and cannot do.” The hospice movement defines its identity as grounded in caring for the ‘good death’ against a caricature of ‘bad’ biomedical care. In practice, hospice staff leverage “hospice philosophy” to better align institutional goals and patient care while simultaneously creating new meaning in the tension that arises between them.

Telling and re-telling hospice history

Contemporary hospice is a relatively young invention relative to the scope of medical institutional history. It has enjoyed a fairly meteoric rise in the U.S. medical landscape: hospice was designated as a Medicare benefit in 1982, just fifteen years after the first hospice was founded in the United Kingdom in 1967 (Meier and Bowman 2017). However, hospice began as more of a social movement than a medical institution, heralded by figures who took issue with

the violence of biomedical end-of-life care. Contemporary hospice proponents begin their story with theories of care that arose in the early 1960s through figures like Dame Cicely Saunders, Florence Wald, and Elizabeth Kubler-Ross. In retelling these narratives, the movement builds (and re-builds) a history that makes sense of the present manifestations of hospice care philosophy. The origin story of hospice is not only re-told internally but also serves as a promotional tool to advance the goals of the hospice movement in wider society. Various permutations of this narrative can be found on hospice webpages, in hospice presentations, or foregrounding news articles about hospice—and Amicus is no exception. Amicus’s Community Representatives often travel to local secondary schools to teach students about the importance of hospice. In their slideshow titled “Hospice 101,” the opening slides jump immediately into discussing the contributions of main players in hospice history. And this tale, as Amicus tells it, follows a familiar road for medical and scientific heroes: they do something *differently*.

The most well-trodden portion of hospice history follows a small cast of mythically-heroic figures who laid the groundwork for the first hospices in the US and UK. Amicus’s presentation proudly dubs British nurse, physician, and social worker Cicely Saunders as the “founder of the hospice movement.” Saunders founded St. Christopher’s Hospice—widely considered the first hospice—in 1967 (Meier and Bowman 2017). Simultaneously, she set out to revolutionize the way medicine approached end-of-life care and pain control (Saunders and Clark 2002). One hospice published a webpage honoring Dame Cicely Saunders, recounting the history of her work in celebratory terms (Crossroads Hospice 2017). They pinpoint her time as a nurse in St. Luke’s hospital as a catalyst for her hospice idea: “While there, she became increasingly frustrated with what she felt was doctors’ ambivalence toward terminally ill patients” (Crossroads Hospice 2017). It is at the start of the origin story that the hospice

movement first paints itself in contrast to an “ambivalent”—and therefore uncaring—medical system. In modern times, such narratives evoke a patient lying comatose in a cold, sterile hospital room with tubes sprouting from every orifice. The website “Call Hospice ” plays into this narrative by focusing on one of Saunder’s talks where she “showed pictures of patients who were terminally ill with cancer prior to and after receiving specialized hospice care (California Hospice and Palliative Care Association 2019).” It is against this backdrop of a bad death—and uncaring care—that hospice often constructs itself as a positive force for end-of-life.

Uncaring biomedicine

The Interdisciplinary Group (IDG) meeting had just wrapped up for the day, and the staff were lingering outside the meeting room. One of the nurses turned to the hospice chaplain, Kalysta, saying “You know, I heard that Connie was pretty uncooperative at Hearson.” Connie was a patient who we had just discussed during the meeting. Medically, she was a fairly standard hospice patient with progressive dementia and general physical decline. However, the group had lingered on her file for a few minutes to discuss their fondness for her. They described her as “pleasant” and “agreeable” in affect and swapped stories about her personal history around the table. She had recently been temporarily transferred to Hearson hospital for help with a health issue, where her emotional state had reportedly gone downhill. The nurse continued, “They said she was ripping out her catheter and everything, very agitated.”

Kalysta’s eyes lit up with fury, “Do you know why?” she responded with uncharacteristic aggression. While at Hearson, Connie had grown increasingly confused and began calling for her mother. “Mommy, Mommy” Kalysta imitated, drawing quotation marks in the air with her fingers. “And do you know what those nurses did?” the chaplain exclaimed angrily, “They told

her that her mom was dead!” Connie had refused to let the Hearson care team complete their medical assessments, and her family was “pissed” about the hospital’s inability to handle the situation. Kalysta insisted that the Hearson nurses were always intent on “bringing the patients back to reality”—which, in her opinion, was the wrong way to handle patients with dementia or Alzheimer's. As if to emphasize the magnitude of this bad care, Kalysta reiterated the patient’s personal history: “And you know, she was so impressive before she was ill!” An “internationally published author,” Connie had been working on her fourth bible-study book when dementia had rendered her unable to write any longer. While Hearson’s nurses saw Connie as just another difficult dementia patient, Kalysta drew attention to Amicus’s recognition of the greater scope of her personhood.

Connie’s story demonstrates how hospice care providers may distinguish themselves from non-hospice medical care in everyday care scenarios. Kalysta conjures the Hearson nurses as being overly concerned with “reality,” to the detriment of Connie’s emotional and practical care. Kalysta reasons that their perspective is even detrimental to more tangible medical care, pointing out their inability to complete assessments and deal with noncooperative disruptions. The reality that the non-hospice nurse focuses on is a paradoxically short-sighted one, especially where end-of-life wellbeing is measured explicitly in emotional and spiritual terms. This clashing of philosophies is not limited to institution-institution conflict but also extends to tension between death movements and cultural modes of understanding death.

“We don’t like to talk about death here”

Not only does the hospice movement construct itself in opposition to an apathetic biomedical specter, but it also imagines itself in contrast to broader “American” cultural

sensibilities surrounding death. Supporters of the “death-positive” movement often argued that American culture struggled with discomfort around “death talk.” Catherine spoke often of general issues with the “denial” and “discomfort” around death—issues that she hoped end-of-life movements could solve. As the Bereavement and Volunteer Coordinator, Catherine was responsible for interviewing and onboarding new volunteers, myself included. She was my supervisor and confidant through much of my time at Amicus and was very passionate about humanistic end-of-life care. One day, a potential volunteer stopped by the office to pick up the hospice initiation packet. As I watched from inside the office, Catherine sat the woman down by the front entryway armchairs for a chat. She began to speak about the importance of hospice work, drawing from a pool of inspirational narratives surrounding hospice patients. The woman was deciding between two hospice volunteer locations, and Catherine was working hard to make her passion shine through. In passing, the prospective volunteer mentioned that she had moved to the area after immigrating from Nigeria. In response, Catherine quipped, “We don’t like to talk about death here.”

The prospective volunteer laughed: “We don’t either.” Catherine began to speak about her own Irish heritage and her husband’s Mexican background as examples of cultures more comfortable with death (and therefore, better equipped to handle the process). In the framework of hospice philosophy, accepting death as “a natural part of the life cycle” or being “death-positive” made open discussion of death a near imperative. Many Amicus staff took the position that facing death head-on is the best path for dying patients, hoping to open up possibilities of care through planning for death.

Promoting open discussions around death is one of the express goals of hospice and end-of-life movements. These conversations are as much a component of the good death as they are a

tool to achieve it. In a biomedical system, advance care planning can be understood through frames of risk and surveillance. Risk “problematizes the normal” (Clark et. al 2003), placing even the most healthy biomedical subjects in temporal and physical relation to death. Death-positive movements often emphasize a need to speak to all people about death, as exemplified by the Amicus Representative’s determination to present “Hospice 101” to high school students. We will all die someday, and death-positive narratives remind us that we are all *at risk* of dying poorly regardless of our current physical state. Discourses of risk rationalize the need for surveillance (which often serves to then re-perpetuate risk) (Clark et. al 2003). On the surface, planning for death bears little in common with typical tools of biomedical surveillance, such as cancer tests or epidemiological statistics. However, this process makes knowable “good” and “bad” ways of dying through self-surveillance via individual planning and institutional surveillance enshrined in legal processes.

By design, a hospice model requires a level of death planning by patients and their caregivers. Upon receiving a terminal diagnosis, patients (or their power of attorney) must make the ultimate decision to enter hospice, necessitating some engagement with impending mortality. Through an interview with a social worker, patients and their families must report (or make) an array of care decisions: What funeral home will they use? Who will be the caretaker? Where will they receive care? What medications would they prefer? Who do they want to be present during active dying? Through this process, patients and caregivers are encouraged to imagine their ideal death. As Mara Buchbinder pointed out in her writings on aid-in-dying, “choreographing” death may be productive of new forms of sociality in dying (2018). However, “accepting” death is a prerequisite for death planning, which is often accompanied by the valorization of those who can stoically accept imminent death. Among Amicus staff, I have heard this idea verbalized in

several ways, including being “ready to move on” or “accepting God’s plan.” In fact, an inability to accept the imminent “reality” of death might be marked as a risk factor for a social worker, chaplain, or bereavement counselor.

The conflict between a ‘bad patient’ (or family) who refuses to acknowledge death and the institutional powers of healthcare comes to a head in the signing of a do-not-resuscitate (DNR) order. A DNR order is an order written by a doctor that instructs health care providers not to attempt cardiopulmonary respiration in an emergency. Unlike many hospices, Amicus does not require patients to sign a DNR to receive services. However, patients and their families are strongly encouraged to do so, and staff will frequently discuss strategies for convincing those who refuse. When I asked one nurse about dealing with families who refused to accept their loved one’s terminal diagnosis, she pointed to the DNR as the focal point for these conversations.

Let’s just go to a situation. ‘You know this person is dying and their health is taking a toll. They’re on hospice, but you don’t want to sign a DNR.’ So when you have that situation, you have to bring them to reality. ‘So do you want someone pressing on their chest, breaking ribs? Doing the compressions? And they’re already at this frail state.’ Or, you know, you have to really lay it down for them to visualize what you’re saying. ‘You know, doing all of that is not going to change that diagnosis. It’s just the point of you giving up on that person, and it’s not you giving up, it’s just—it’s trauma that that person is going to endure because you personally are in denial and don’t want to sign that DNR, you know.’ So it’s like a catch, but it happens, it happens to the best of us until...And I say that because you don’t know. But when you bring that person back after the chest compressions and the broken ribs and their trauma. And then knowing—or not knowing—what happened or what took place. Where to next? What’s the quality of life going to be after that?

Through its institutional and legal power, the DNR allows for a shifting of goals away from preserving life, typically the domain of non-hospice biomedicine. In a medical system that often imagines patient autonomy through the lens of consumer choice (Mol 2008), the preservation of life is viewed as the natural (legally protected) state. Staff often attribute a reluctance to sign a

DNR as fear of “giving up” or not accepting the reality of imminent death. Though I have heard less gracious people describe such actions as selfish, the nurse I spoke to emphasized how this reluctance might come from an intention of care (“it happens to the best of us”). However, she evokes the violence of biomedical treatment (“pressing on their chest, breaking ribs”) to advocate for accepting death as the superior care model for dying patients. Convincing patients, caretakers, and families to align with a hospice-informed perspective is part of the care obligations of hospice staff.

Institutionalizing a counter-institution

Though the history of hospice pushes against traditional institutions, it fails to interrogate the place of institutions in death. The website 1-800-HOSPICE™ promotes the virtues of hospice through a collection of articles, including one titled “A History Of Hospice: A Timeline Of One Of Medicine’s Oldest Disciplines” (Christophe 2016). The post explains “The concept of hospice – the treatment of the terminally ill – has had a long existence in Western culture (Christophe 2016).” The word hospice comes from the Latin “*hospes*,” which was used to refer to lodgings for 11th-century Christian pilgrims, many of whom were sick or dying (Saunders and Clark 2002). Some more secular recountings of hospice history—including Amicus’s presentation—tend to forgo this particular “point of origin” and begin with the founding of the first hospice by Dr. Cicely Saunders. Regardless, the hospice story centers on medical institutions, healthcare professionals, and academics. The emphasis on hospice as an institution (or counter-institution) naturalizes the presence of professionals at the end of life. In his examination of the end of life as a civic matter, Allan Keellehear critiques how these narratives

neglect that “most care of the dying and bereaved in societies and throughout human history was performed by ordinary people in the communities in which they lived” (2020, 117).

In the tradition of similar counter-institutions of the 60s and 70s, the early hospice movement presented itself as an alternative to the established order of care. In 1985, Claire Tehan—an early adopter of hospice in the U.S.—published the article “Has Success Spoiled Hospice?” in which she examined “the evolution from hospice movement to hospice industry” brought about by the introduction of the Medicare benefit. The hospice Tehan helped found in 1977 had grown from a grassroots effort of five professionals and 20 volunteers into a million-dollar program staffed by 30 professionals and 100 volunteers (Tehan 2003). She described an adjustment to “economic reality” as the hospice model transformed to contain costs and establish a uniform standard of practice (Tehan 2003). Although these changes varied across hospices, they included stricter criteria for patient selection, decreased interdisciplinary contact, slashed bereavement programs, and a push for less inpatient care (Tehan 2003). Despite this, Tehan takes an optimistic outlook on the future of hospice: “it is possible to combine good management principles and the core of hospice care (2003).”

In the 1986 issue of the *International Journal of Health Services*, Emily Abel paints a much less rosy view. Abel argued that many of hospice’s more radical ideals had been compromised by a move toward assimilation with existing healthcare structures. Abel points out several similarities between hospice and other counter-institutions of the time like free schools: “nostalgia for simple, old fashioned ways, dissatisfaction with bureaucratic and authoritarian institutions, faith in the power of nature, a termination to avoid domination by experts, and a desire to improve the quality of personal relationships (1986, 71).” And like free schools, “they were forced to rely on mainstream institutions for resources, political acceptance, and personnel

(Abel 1986, 71).” In the past 35 years, hospice has only further exploded in popularity and grown even more entrenched in healthcare institutions. This process has shaped hospice’s understanding of patient personhood and provided a roadmap for staff to navigate institutional structures to deliver care.

Are they dying?

As both Cohen and Abel mention, one of the most visible ramifications of Medicare’s restructuring of hospice is the standardization of who qualifies to be a hospice patient. As the medicalization of dying has progressed through history, the question of who qualifies as “dying” has increasingly been defined under the authority of the state (Kellehear 2007). From the denial of dying status to some terminal patients to the imposition of dying status on others, the boundaries of dying can be sites of violence in hospice and beyond. For patients to receive or continue receiving hospice care, they must meet certain regulatory standards that indicate a prognosis of six months or fewer. As one nurse laid out for me quite frankly, “you either qualify or you don’t.” At IDG meetings, Amicus’s clinical director would review the list of the patients approaching their hospice “recertification” deadline to ensure that they still qualified as dying. Patients who show significant improvement may be “decertified” (removed from hospice services) since dying status leans heavily on understanding people in temporal relation to death. Other patients were decertified when they chose to pursue life-saving treatment instead, betraying both the cost-saving rationale for hospice and the imperative to “accept” death. Certification was one of the facets at which staff mediated the boundary between patient care and institutional structures.

In most cases, staff were celebratory when a patient “showed improvement”—often defined by physical ability, social engagement, or increased temporal distance from death. A nurse once joked happily about a man who had begun stealing food off of other people’s plates in his nursing home after he had previously eaten nothing at all. Other times, reports of a patient’s improvement would bring a tense silence over the meeting room. Many staff viewed the decertification of patients as a threat to their wellbeing. Insurance structures were eager to remove patients from care if they no longer met the criteria of “dying,” likely to save costs on treating patients who were too healthy. When I first met with Amicus administrators to discuss the logistics of my research, their primary concern was the risk of my writing leading to unintentional patient decertification. I was instructed to be careful to avoid overly optimistic interpretations of a patient’s condition, even if I was trying to praise the care hospice provided. Many patients did not have a highly functional support system outside of hospice care, and leaving the service could be disastrous for their care. Not only might they be at risk of receiving very little formal care at all, but some were at risk of being lost altogether from systems of care. Other patients, the clinical coordinator insisted, left the service only to rapidly decline in condition due to poor care and end up back in hospice services. The risk of decertification hung over every entry in the medical records or meeting report.

“It was like he was selling me a car”

Even when patients fully qualify for the care promised by the state, hospice care may still fail to live up to the promises made by lofty philosophies. Attempts to ensure a “good death” may be frustrated by family dynamics, payment systems, institutional constraints, and practical challenges facing Amicus Hospice. Incidences of failed care not only have tangible

consequences for patients and the institution but can also call into question the legitimacy of the carefully constructed hospice identity. I watched one particular instance of failed care unfold over several weeks, through decision-making sessions at IDG meetings to the aftermath in the bereavement office.

This particular case was an unfortunate confluence of strained resources, institutional constraints, and situational misfortune. The patient's primary caregiver was her husband, whom the staff universally described as the "glue that's holding everything together." However, he was simultaneously tied up in a whirlwind of other care obligations. Both of the couple's adult children had significant physical disabilities and were incapable of caring for the patient. While he tried to care for his dying wife, the husband also found his time occupied by caring for his own mother. "I got to experience her mother-in-law's absolute dependence on her son," one nurse commented, "it's very sad." Despite his competency, the group doubted that he would be able to provide adequate home care without assistance. When the family had enrolled in hospice care, a miscommunication led them to believe that the nurses would be visiting the house twice each week (instead of the standard once-a-week visit). In the IDG meeting that week, the clinical coordinator insisted that Amicus simply did not have the staff to offer additional visits. Enrollments were high, and nursing staff were hard to come by, especially since one nursing assistant was on leave due to a recent job injury. Yet, the group agreed that the family did not have the resources to arrange full-time care, and inpatient respite care was limited by Medicare policy. A few nurses agreed to try to fit some extra visits into their already overly-strained schedule, but the consensus seemed to be that there was little to be done.

In the end, the care Amicus Hospice offered fell short of the family's expectations. Several days after the patient passed, Catherine called the husband for a standard bereavement

intake. After she finished the phone call, she confided in me that the husband had been very disappointed in hospice care. Solemnly, Catherine described him as “factual and calm” despite his disappointment. He called out the man who “sold” him the hospice service, telling Catherine “it was like he was selling me a car; he promised a lot of things he didn’t deliver.” For example, he had been promised that a nurse would be present eight hours a day when his wife was actively dying—but that never happened. Amicus was responsible for calling the ambulance for the patient, and a nurse was supposed to arrive with the ambulance. When the ambulance arrived without the nurse an hour early, the husband initially thought nothing of it. However, when he called Amicus to tell them about the ambulance, he learned that the nurse would not be coming because she had mistaken the day in her schedule. Though he had positive experiences with Amicus’s palliative services, he was deeply disappointed in hospice, telling Catherine “I wouldn’t recommend this service to anyone.”

Catherine was visibly distraught by the idea that hospice services had mishandled someone’s end-of-life care. She told me, “You know, we send them a survey.” Every person who enrolled their family or loved ones in Amicus’s services received a survey after the patient passed. The results of the survey were sent to regulatory bodies for Medicare and Medicaid and were crucial to maintaining Amicus Hospice’s official certification. At the following week’s IDG meeting, Catherine curtly reported to the group that hospice “was not a good experience” for the family. She seemed hesitant to go into further detail (perhaps not wanting to call out the failures of her colleagues), but the clinical coordinator, Marsha, prompted her to share the husband’s perspective with the group. Though some of the failures could be addressed directly, such as the confusion with the ambulance, other aspects were inherent to a hospice system that leans heavily on informal care obligations. Confronting these failures challenges a hospice

identity that claims to oppose biomedical violence while leading a universal cultural reimagining of death.

Identifying hospice

The lofty images of hospice philosophy touted by Amicus Hospice center holistic pain relief and social death. These ideas have been shaped by the counter-institutional goals of its founders and ongoing opposition to hospitalized death. However, hospice care is increasingly affected by institutionalization and regulation, as the state's goals for hospice care often differ from those of individual care workers. The resulting ethic of care is formed by the tensions within hospice identity. The where, when, who, and how of the "good" death is constantly redefined. The construction of the hospice movement is key to understanding the care decisions of Amicus staff.

Section 2: Hospice-in-Place(making)

“Hospice is...not a place”

At each IDG meeting, the team spent a significant amount of time reviewing the new enrollments as a group. The process began with the nurse case manager, who presented a review of the patient’s demeanor alongside their medical history. In one instance, the nurse described a new patient as “pretty much withdrawn, only talking with his ‘boss’—his wife.”

“I love that,” another nurse laughed.

“I think he’s depressed and just wants to get it all over with.”

The social worker had talked with his wife, who claimed that the secret to her 53-year-long marriage was “spending a lot of time apart.” She still worked as a beautician outside the home several times a week, which one nurse speculated helped her recover from the stresses of caregiving “and keep her marriage long.” The patient was a heavy smoker, with ashtrays scattered around his house. A “smoking care plan” was listed on the medical chart, since the nurse case manager was hoping to help curb the behavior. However, the clinical coordinator suggested instead switching it to a “safety care plan.”

“Do you think you’ll be able to make him quit?” she asked incredulously. The clinical coordinator was more concerned about the possibility of the patient catching himself on fire from smoking too close to his oxygen tank. “Tell him that you won’t visit if he doesn’t stop smoking when the oxygen is on; we won’t have you blowing up,” she told the nurse sternly. Home care at the end of life requires navigating complex dimensions of authority in caretaking alongside ideas of a good dying process.

The hospice-in-place model is deliberately outlined as a defining feature of Amicus' philosophy. One of the "Ten Myths of Hospice Care" listed in the Amicus volunteer manual is "Hospice is a place." The explanatory text below the bold print reads "Hospice is a philosophy of care, not a place." Through my fieldwork at Amicus, I have come to agree with the manual—hospice is not "a" place. Instead, hospice is many places. Hospice is physically multilocal: the spaces of Amicus hospice care are geographically dispersed across the region, spanning residences to nursing homes. However, hospice is also discursively multilocal. Hospice is constructed at a contested nexus of translocal state interests, local identities, ideologies of dying, and intersubjective meaning-making. For staff members, hospice is an exercise in placemaking care. Placemaking is a care strategy aimed at preserving patient personhood while navigating contested authorities of place and surveillance. Through caring for death, care workers construct hospice as a kaleidoscope of many places and processes experienced across space and time.

To engage with an anthropology of place, I must first define the terms of spatial analysis. In her ethnography of Alaskan landscapes, Sandhya Ganapathy explores how translocal spatial formations imposed by the state are contested by local Native communities through grounded engagements (2013). I borrow from her work in defining space as existing between the physical environment and imagination, "emerging through the interplay of the following: those environments; political, economic, and cultural institutions, ideologies, and practices; and individual and group experiences and identities (Ganapathy 2013, 98). Place arises from space as a particular set of temporal and intersubjective engagements (Ganapathy 2013). In this context, "translocal" construction of place occurs at a distance, absent from local or embodied meanings (Ganapathy 2013). For the Gwich'in Athabascan communities, though the Arctic Refuge is a space constructed by external political authorities, the refuge "overlaps and intersects with many

indigenously constituted spaces and places (Ganapathy 2013, 108). I also draw from Margaret Rodman's rethinking of Foucauldian notions of place through her fieldwork in Melanesia (1992). At the conclusion of her piece, Rodman identifies the funerary feast as a primary example in exploring the intersection between power and social constructions of place (1992). For one hundred days, the deceased spirit remains in place, watching over the proceedings. Gift-giving, narrative placemaking, and power structures craft a new social landscape as the transfer of land ownership occurs and funerary ceremonies separate the deceased from the place (Rodman 1992). Placemaking in hospice care is similarly subject to power structures and contested meanings, which are bound up in the social transformations at the liminal space between life and death.

Constructing hospice space under Medicare

Before we can examine placemaking, we must first address how hospice space arose from historical, social, and political transformations. Over the past several decades, Americans have been changing where they die. From 2003 to 2017, the proportion of Americans dying in hospitals decreased from 39.7% to 29.8%, while the proportion dying at home increased from 23.8% to 30.7%—surpassing hospitals as the most common location of death (Cross and Warraich 2019). This trend was a turnaround from the 1900s, where increased urbanization, access to medical care, and the medicalization of death made the hospital the new standard place to die (Cross and Warraich 2019; Kellehear 2007). The trend towards home death has been driven in large part by the burgeoning popularity of hospice: the number of Medicare beneficiaries receiving hospice care increased by 17% from 2012 to 2017 (National Hospice and Palliative Care Organization 2020). Between 2010 and 2020, the 65-and-older population grew by over a third, presenting United States families and social institutions with the question of how

to handle the rising cost of elder care (United States Census Bureau 2020). Medicare recipients often incur the highest costs in their final year of life, making some even more anxious about the impending ‘death boom’ (Riley and Lubitz 2010). Hospice’s popularity, therefore, has no doubt been furnished by its economic accessibility. Medicare offers hospice free of charge to qualifying terminally ill patients who “sign a statement choosing hospice care instead of other benefits (Medicare.gov 2022).” On its face, the localization of dying to the home represents a (rare) confluence of the state’s economic interests and humanistic ideals of care. However, a look back at the history of the hospice benefit reveals tensions in the creation of hospice space.

By the 1970s, the federal government was growing increasingly wary of the cost of death. In 1976, a third of Medicare expenditures were put toward patients who died (Miller 1995). Federal interest in the explosive popularity of hospice picked up in the late 1970s. The General Accounting Office sent a report to Congress detailing possible Medicare savings and the Health Care Financing Administration opened a cost-and-quality study of 26 U.S. hospices (Miller 1995). A bill that would make hospice a Medicare benefit moved through the House and Senate in the early 1980s, before finally being passed as part of the Tax Equity and Fiscal Responsibility Act in 1982 (Miller 1995). As the Reagan administration brought about a widespread culling of social programs, the hospice benefit served as a politically advantageous show of federal humanitarianism while simultaneously cutting costs (Miller 1995). Most critically, this benefit required that the bulk of hospice care take place at home (Medicare.gov 2022), in contrast to the residential hospices first founded by Dr. Cicely Saunders (Saunders and Clark 2002). Though the expected savings did not materialize immediately (Miller 1995), they are very evident in hospice’s contemporary form. A study from Duke University found that hospice reduced Medicare spending by an average of \$2,309 per person compared to non-hospice end-of-life care

in 2007, largely by avoiding expensive hospitalized dying through home care (Taylor 2009).

However, the decision to use the Medicare hospice benefit is correlated with higher informal costs for families and caregivers (Taylor 2009). While the original proponents of hospice set out to combat the abandonment of the terminally ill, the federal government paradoxically took on hospice as primarily a means of offloading the cost of caring for them.

Within hospice policy, the state imagines the home as a place where daily care is built into the landscape. As a result, home hospice care leans heavily on an assumption of uncompensated familial care structures. This is a built-in feature of the Medicare benefit (and one of its greatest cost-savers), which requires that at least 80% of hospice care be provided in the home or long-term care facilities with options for inpatient “respite care” for 20% of the duration (Medicare.gov 2022). Wealthier patients can afford to hire home care aids or pay for nursing home care (though the latter is less appealing for many families). Amicus’ patient population spans a broad range of socioeconomic statuses, including many patients who are uninsured, underinsured, or otherwise unable to afford additional care. For patients who are not actively dying, nurses visit weekly. Outside of those short windows, the responsibility for care often falls squarely on the shoulders of familial caregivers. Other times, the patient provides their own daily care independent of any caretakers. As Amicus hospice staff confront the realities faced by home caregivers, they imagine hospice as a place in relation to the expectations of care set by the state.

As the nurse moved through the patient list at one IDG meeting, the group encountered two contrasting cases of home caregiving. For one family, a nurse attested that “the daughter is very knowledgeable about taking care of her mom.” When the daughter had to step away, she would call upon a large network of nieces and grandchildren to sit with the patient in her

absence. The group seemed pleased to hear how the daughter was planning a dinner with the patient's siblings, providing social as well as practical care. However, just one number up the list, another patient's daughter was subject to a less idyllic experience. At first, the daughter had been very irritable, snapping frequently at hospice staff and her mother. The nurse noted that the daughter was "overwhelmed," but was "starting to become okay with taking care of ADLs." In the daughter's conversations with the chaplain, she revealed that she felt like "the monkey's on her back," especially after quitting her job to care for her mother. However, in recent interactions with the social worker, she had "calmed down" and apologized for her treatment of the hospice staff members. The daughter had come to an agreement with her employer and landlord to reduce financial stress and attributed her change in disposition to these "solid" factors. Amicus staff members construct the home as a place where successful familial care can produce both material support and fulfillment of the socialities of a good death. However, the home is simultaneously understood as restrictive and draining, pulling caretakers away from the emotional, economic, and social landscapes of non-hospice life. Even in situations in which caretakers are hostile, Amicus hospice staff construct the expectations of the home hospice space (rather than the individual) as a place of both struggle and possibility.

"More than we could have asked for"

Despite the challenges of home care, the movement of dying people from the hospital into the home is driven by more than policy alone. Entering hospice care is framed as a voluntary choice, at least for patients ruled competent enough to make their own medical decisions. When partnered with expansive pro-hospice public campaigns, many participants require very little convincing. Dying at home is desirable for many: The Kaiser Family Foundation reported in

2017 that seven in ten Americans would prefer to die at home, though only 41% expect to. The chance to die at home was often cited as a primary consideration for those choosing hospice (Waldrop and Meeker 2014). Amicus' marketing team seemed to be well aware of this appeal, as the choice to have at-home care featured prominently on Amicus's advertisement materials. On the lower banner of their website's FAQ page, a testimony from the daughter of a patient reads "The fact that my dad was able to **comfortably pass away at home**—with all of his kids and wife at his bedside—is more than we could have asked for especially in these unique times (emphasis original)." This quote champions home death as an opportunity to fulfill certain kinship modalities: "with all of his kids and wife at his bedside." However, the testimony evokes a subtle precariousness in the insistence that a home death "is more than we could have asked for," a nod to hospice as an escape route from the undesirability of a standard hospital death.

The appeal of home care is constructed against fears of a hospitalized dying. This phenomenon runs parallel to the way hospice philosophy contrasts itself to biomedical thought as discussed in section one. Though only nine percent of Americans would like to die in a hospital, 24% expect to (Kaiser Family Foundation 2017). In a hospital, surveillance is one of the primary forms of care—to the detriment of patient personhood and sociality. This includes technical non-human surveillance through various monitors and frequent testing (the results of which are charted in medical records) (Clark et. al 2003). Hospital rooms are controlled environments with minimal privacy, facing a hallway where staff regularly come and go. Nearly all hospice care patients enter the service after periods of sporadic or extended hospitalization due to long-term illness, which can contribute to their desire for home care (Waldrop and Meeker 2014). The imagined 'bad' hospital death may be paradoxically sedated (preventing engagement in the sociality of death) and painful (due to aggressive treatment in the struggle against death). The

same surveillance intended to care and protect from the uncertainties of illness pulls the patient away from the social world. The ability of Amicus staff to place-make home hospice is contingent on both establishing its proximity to the hospital (in terms of surveillance) and simultaneously placing it in opposition to the hospital (in terms of personhood).

When handed a terminal diagnosis, patients are allowed—or even encouraged—to move from the highly controlled hospital environment to the home. As I discussed in the previous section, biomedical authorities (often physicians) determine that a patient is officially “dying” according to criteria set by the state. The relaxation of biomedical surveillance ethics is due primarily to a shift in the goals of care. When a patient decides to begin hospice care, death is no longer a bad outcome. Instead, ‘dying poorly’ is pathologized in relation to ‘dying well.’ Instead of preserving life, medicine turns its focus to palliative care and comfort measures. At Amicus, the broad definition of “comfort measures” gave staff the authority to not only provide a range of individualized care but also justify increased patient autonomy. Comfort measures then could be used to care for patient personhood, which may have been diminished by the medicalization of aging and dying (Ballenger 2006). Offering personhood-based comfort measures often involved building upon the meanings embedded in the home as a place of identity-making.

For many patients, the home represents ‘American’ individualist ideals of authority, ownership, and independence. One nurse reported that Frank, one of her patients, was reluctant to move out of his home despite being at a significant fall risk in his basement. Though she had raised concerns many times, Frank insisted on waiting until he sold his house before moving out. When the clinical coordinator heard this story during the IDG meeting, she suggested that the nurse try to convince the patient to live with his daughter while he sold the house. But the nurse just laughed and explained that Frank was already well aware of this option. In the nurse’s

opinion, he was intentionally stalling the move in order to retain his independence. Despite doubting his motives, no one seemed eager to force Frank out of his house while he was capable of maintaining independence. Frank's emotional attachment to the home—and the autonomy it represented—superseded the physical danger presented by the environment. In delivering care at home, hospice staff balance authorities of health and safety. Frank's story also demonstrates how the home hospice is constructed intersubjectively through bargaining with and among care staff. In their attempts to construct a care space that attends to personhood, Amicus staff often found themselves mediating a delicate balance between patient autonomy and safety.

“You're in control”

One day, I was in the volunteer office putting together a “birthday bag” as a gift for a patient, complete with handwritten cards and kitschy birthday decorations. As I organized the items in the brown paper bag, I looked apprehensively at the Hostess cakes I had been told to include. While I was observing inpatient facilities for general surgery a few years ago, I had quickly learned that the matter of patient intake was of grave concern and strict regulation. Noticing my hesitation, Catherine laughed and reassured me that it was fine for the patient to enjoy himself on his birthday, even if the cakes were not strictly in line with his medical diet. It is common practice for Amicus to relax food and drink restrictions for patients when they enter hospice service. The nurse case manager Taylor emphasized this practice often as a part of her own care plans:

The way I look at it is: they don't have anything to lose. If that person wants to smoke, let him smoke. Let them have what will make them happy, like desired foods. Let them have it. It's something that they've always wanted, and they've been told—depending on how long they had this chronic disease—they couldn't have it. At this point in their life, let him have it. The damage is done or not, but just let them be happy with the choices that

they can still make at this point in time. And that's how you do it. You just let it go. Let them live. The quality of life or whatever they choose to do at that point, let them have it.

Her explanation engages with multifaceted understandings of comfort care as extending beyond medical pain control. At the end of life for hospice patients, staff imagine a very limited temporal horizon (“they don’t have anything left to lose”). Though Svendsen et. al considers temporal imaginaries of recovery crucial for the life-making of dementia caretakers (2013), hospice turns this process on its head. By instead imagining the temporal proximity of death, Amicus caregivers are able to chip away at the de-personalization imposed by surveillance and medicalization.

Part of the care expressed in the Hostess cake birthday gift no doubt originates from the joy the patient would get out of eating tasty sweets. However, as Taylor explains it, the key focus is “desired foods”—not just delicious foods. She nods towards the paternalistically restricted worlds of those with chronic disease (“depending on how long they had this...”), a charge doubly imposed on the aged (Kane and Kane 2005). She prioritizes telling the patient that they are “in control” of their care and believes that good caretakers will “just let it go.” In Taylor’s understanding, patient happiness stems not only from the outcome of these choices but the ability to make the choices themselves. In this framework, the Hostess cake is also an act of care in that it gives the patient *the choice* to eat something he would normally be denied. The key role of hospice staff here is to create a place within institutional authorities where patient autonomy is possible. Taylor described how her patients will tell their caregivers, “The nurse says I can have it so you can't tell me I can have it, you know.” She operationalizes the authority granted by her position with the medical system to facilitate patient autonomy.

In reference to my discussions of personhood in the introduction, traditional definitions of individualist personhood privilege the ability to act autonomously. According to this framework, staff care for personhood by constructing a hospice space where patients have the authority to make their own decisions. However, I wish to extend this definition to include the intersubjective experiences of performative bargaining. Taylor spoke to me about navigating control issues for a patient who refused necessary care.

I had one patient where she didn't like to be turned. I'm like 'you don't want to be turned, sweetheart,' and she just look at you with those staring eyes, glaring. 'But when you think about it, we can't get this done unless we turn you' and then she looked and you could see the gaze go down just a little like, 'OK, I'm not as angry as I was a moment ago, because you said that.' But I said, 'but you're in control.' And then when you say that, it's like 'OK, do what you want.' You have to play the the mind game in the sense to say 'you're in control,' and once they know that they're in control—because so many things have been taken away from them that if you can just tell them that you're in control. I think that makes a difference, as opposed to just saying 'no.'

Though the ultimate outcome of the interaction was unaffected, Taylor cared for patient personhood through a willingness to engage with the patient's desires. She acknowledges how the patient's distress ("you don't want to be turned, sweetheart") is compounded by a lack of agency in infirmity and old age ("because so many things have been taken away from them"). In this scenario, "you're in control" serves not to transfer agentive power but to offer the opportunity to perform the intersubjectivities of personhood. Amicus staff take up the responsibility of creating hospice as a place that engages the personal meanings of the home with delicately balanced structures of authority.

Maintaining equilibrium

“I thought that because I came from hospital that I would be more comfortable in facilities, and I’m not. I’m more comfortable in people’s homes. I really like it a lot.” I was speaking with Jane, one of Amicus’s nurse practitioners in charge of palliative care. She was responsible not only for arranging palliative services for patients but also for facilitating their decision to move to hospice. Her practice experiences before Amicus had ranged from a major surgical intensive care unit to an orthopedic spine practice. This role was her first time working outside a medical facility, and she spoke extensively on how her approach to care had changed. “I actually have my own little camping chair,” she proclaimed proudly. While in training during her early days with Amicus, she found herself sitting in on a family conversation about transitioning a patient to hospice.

Their house was really small and kind of cramped, and they didn’t have chairs for seven people. And so, [the patient’s] wife was actually sitting in the kitchen. And so, patient, nurse, me, two sons.

Jane pointed her finger in a circular pattern to draw how the gathering was organized in the living room.

And then, she was kind of like in the kitchen. I kind of deeply regret the fact that his wife wasn’t closer. Because you could tell she couldn’t hear as well, and so one of the sons was kind of repeating everything to her. Anyway, now I bring my own chair—one of those little tripod camping chairs—so that families can be comfortable and sit where they normally sit. And then, I’m like the visitor, kind of trying to sit near the patient so they can hear me but also trying to be respectful of everybody’s space.

Just as Jane’s camping chair is nondisruptive to physical space, Amicus staff often work to be nondisruptive to established social orders of place in the home. Ideally, by prioritizing pre-existing configurations of the family and home, hospice-in-place can live up to the picturesque image promised by the website advertisement “with all of his kids and wife at his bedside.”

Many Amicus staff viewed preserving the existing environment, both physical and social, as an important part of their role. However, tensions arose when translocal constructions of hospice by medical authorities conflicted with local understandings of the home. Jane had struggled with one particular patient whose choice of residence conflicted with her medically authoritative opinion of what would be ideal for his care.

I think that one reason we were ordered to go and see him was that he was refusing—or declining, however you want to say it nicely—long-term care placement. And because he had all of his faculties, you can't force someone into a nursing home. He had money, but he wasn't willing to pay for anyone to stay with him. So, he had this person that he would allow to come in for three to four hours a day, but that's it... There is no more care to get in the home because he wasn't willing to pay for it. And we can't move somebody who has capacity, so I don't think I helped him. He eventually started declining to get out of bed with his helper, so he could no longer walk to the bathroom or get cleaned up or anything like that. And about a month later, he died. Not on hospice, on palliative care. And he stayed a full code, because he wanted everything done, and he felt like that if he started to decline, [he could] call 911, he would be alright.

Though the conditions of dying aligned with the patient's wishes, Jane considered his case to be a failure of care. His living situation put him at risk for difficult or bad care, in which he could not have his basic necessities fulfilled. However, her inability to “help” him also stemmed from his resistance to moving toward the ideals of hospice care. In fact, he never entered hospice care at all, asserting his own constructions of dying in place instead of hospice-based configurations.

As she conjectures as to why Amicus might be “ordered to go and see him,” Jane goes as far as to implicitly recognize palliative service's role in an institutional apparatus that encourages patients to make the “right” decision about their care. Jane understood the patient's insistence on remaining in the home as a desire to exist outside the constraints of medical and social institutions, couched in personal individualism. Like Taylor, she believed past experiences of paternalism fueled his desire to make his own decisions: “I think that one time he had short-term stays in nursing homes and maybe wasn't allowed to eat what he wanted to eat or do what he

wanted to do.” He did not accept death through the symbolic process of signing a DNR and instead, continued to pursue any possibility of life-prolonging treatment. He also rejected his role as an object of care for others, whereas hospice often boasts the most social death as ideal. When asked about why he might have chosen this path, Jane commented, “you know, he’s lived alone for the last 20-30 years and just having that mentality of ‘I don’t need anybody to help me with this. I don’t want anybody to help me, because I never had help in the past.’” The patient’s desire to maintain his personal conception of permanent personhood grounded in place was incompatible with the symbolic and logistical goals of end-of-life care.

Institutional care and safety

Though many Amicus patients lived in private residences, a significant portion resided in long-term care facilities. The conditions in these facilities (and the degree to which patients considered them “home”) varied widely. Many patients—and some staff—found the idea of dying in a LTC facility less desirable. When I asked one Amicus marketer about her decision to work in hospice, she cited her negative experiences with long-term care in the past:

I was really close with my grandma; she was in and out of facilities. I saw facilities and hated them, so even when I was eight years old, I always told them “can I please work here.” I wanted to work there because people looked miserable and no one did anything there.

Staff, patients, and families at Amicus sometimes seemed to draw from the image of LTC facilities as neglectful, impersonal, and controlling. When I asked Jane whether she thought long-term-care facilities or the home were better for end-of-life care, she seemed divided.

The behavioral problems are worse in long-term care facilities, while safety problems are worse in the home. One man turned on the faucet in his kitchen and just left it on, same with the stove. And he lives alone. There’s safety concerns. If he was in a nursing home, he wouldn’t have the opportunity to do that. But his agitation would be worse because

he's lucid at times and wants to go do what he wants to do. Every time somebody gets in his way, he gets really agitated.

On the whole, LTC facilities were considered to offer less independence while ensuring greater safety. As discussed in the introduction, medical facilities enact care through surveillance and restriction. For hospice to be a legitimate alternative to the hospital, staff must construct the hospice place as a safe environment.

As a result, some Amicus nurses considered LTC facilities to be the preferred space for hospice. Taylor had previously worked extensively in nursing homes before joining Amicus hospice. She saw many advantages to doing hospice in LTC facilities over homes, due to the differences in surveillance, professional authority, and the built environment.

The difficulty of going into the home is in the home environment, you have to observe the safety. First and foremost, it's all about safety. It has to be a safe environment. Homes are not under any regulations. Facilities are under regulations. So if your patient is immobile, and there's carpet on the floor, that's a safety hazard. So, you have to make the suggestion to them change their home setting to accommodate the patient. And sometimes, that's not easily taken in...In the facility, yeah, they have it. I mean, because they don't have carpet and where they do have carpet, you don't take the patient to the carpet...Home environments are not always conducive to what is needed for that patient. Facilities are under requirements, regulations, and you can tend to get assistance. And in their facility, you have nurses that always there, they're your eyes and your ears when you're not there. The home you have to depend on that caregiver, that's your eyes and ears when you're not there, so just you just have to be mindful. Think outside the box, anticipate what could be going on, or anticipate the need for this, between this time and the next time that you're coming back. But in a facility, you always have someone there.

LTC facilities (and the staff that operate them) derive some of their “safety” through “regulations” and proximity to state control. Facility nurses are seen as reliable apparatus of surveillance while dealing with home caregivers requires anticipation and creativity. Existing home environments (both built and social) may need to change to make a “safe” hospice environment. Though the dying status can open up new worlds of anatomy for patients, constructing hospice as a “safe” place can seem to restrict it. However, I understand the process

of constructing “safe” as a process of intersubjective recognition. In Medicare’s attempts to cost-save through home hospice care, the state imagines the dying as less valuable recipients of extensive care. As nursing staff work to construct a safe place for dying, they recognize patients as valuable subjects of care. However, despite ideals of safety in LTC facilities, daily reality exposes the precariousness of translocal placemaking.

Navigating elder abuse and neglect in long-term care facilities had always been an issue for Amicus hospice, but the issue seemed more magnified than ever in light of staffing shortages during the COVID-19 pandemic. During one IDG meeting, the clinical coordinator revealed that one facility had left the memory ward completely unstaffed when no CNAs were available, leading to several patients missing their medication. Several people around the table let out a soft “oh,” shocked into silence for a moment. Outwardly, everyone seemed frustrated at the lack of adequate care. However, it seemed that everyone was equally frustrated by the knowledge that such lapses came from the same lack of healthcare personnel that Amicus also faced. The coordinator revealed that the same Sunday, the facility had called 911 for a lift assist for a fallen patient due to insufficient staff to help out. A nurse interjected in disbelief: “At a facility?” The expertise and equipment necessary to lift a patient were seemingly a given at a facility. Another patient at the facility had been assigned to bed rest only, but when the nurse arrived for a visit, his room was empty. She found him wandering around the dining room, where the staff claimed that they had not known about his condition (despite several recent falls). At a different (but similarly understaffed) facility, a woman had begun to raise concerns to the hospice group about the quality of care her father was receiving. Taylor told her, “we’re guests in that facility, there’s nothing we can do.” The woman requested more frequent visits from hospice instead, but the nurse seemed hesitant to agree. “We’re already hurting for staff,” she reasoned, “but I didn’t tell

her that.” These ruptures in the LTC facility “safety” served as reminders of the limits of hospice placemaking, especially in spaces dominated by other authorities. The hospice place is bounded by social structures, power, and temporal configurations of death.

The uncanny corpse

Amicus gives all home caregivers a “care box” coated in golden foil and tied up with red plastic rope. The contains a variety of brochures, packets, and handouts detailing what to do during “active dying” and immediately after the death of the patient. The box also contains a little plastic bag with a bottle of mouthwash, a tube of mouth moisturizer, and a handful of oral swabs to use to help with comfort in the final stages of dying. Amicus promises to have an on-call nurse available for a death visit within one hour and one of the resident physicians to certify the death not long after. Within a few hours, the body is removed from the residence or facility and taken to the funeral home, where it awaits burial. Much of the idealism around a home death evokes the sociality of the dying—the patient’s ability to interact with the social environment of the home or to imagine themselves as a whole person. However, technoscience draws a seemingly strict line between the living person and the body, where death is an event that begins with a person and ends with a corpse (Lock 1996). As a result, hospice place becomes deconstructed soon after death occurs and the patient ceases to inhabit the space. For the corpse to still exist among the living is uncanny, outside of specific institutional contexts like funerals. Though hospice often encourages pushing dying into the social realm, the dead body is often considered non-social and unclean.

Freud presented “death and dead bodies” as one of the principal examples of “the uncanny” (1919). The uncanny is described as “in reality nothing new or alien, but something

which is familiar and old-established in the mind and which has become alienated from it only through the process of repression (Freud 1919).” Though I do not take a psychoanalytical approach here, Freud’s definition holds striking similarities to my own. I want to draw upon the ways that uncanniness represents the tensions between the expected and unexpected formations of place in death. The uncanniness of the persistent social “living” of the dead body plays alongside hospice’s ideal of honoring the desires of the deceased. During one of my first days at Amicus, I witnessed a conversation between the clinical coordinator and the receptionist about a patient for whom the staff had just completed a “death visit.” The coordinator recounted that the patient had “lived in” their armchair while they were on hospice service and eventually died there. When the nurse walked into the room after being called for the death visit, the family was laughing and joking around the armchair as if it was a normal day. Both the receptionist and the coordinator seemed a bit uncomfortable, and silence fell for a moment. Then, the receptionist concluded, “that’s how she would’ve liked it.” “Yes, yes,” the coordinator replied emphatically. Stories like this were not uncommon when discussing death visits, but institutional control over the body presented new challenges.

One day, Catherine was making calls to bereaved family members while I sat beside her working on medical records. One call was to the daughter of a patient who had died several months earlier. The woman was distraught that she could not yet bring herself to part with her father’s ashes, despite the encouragement from those around her to let them go and move forward with her grief. Catherine reassured her that there was no need to do anything and instead, to take her grief at her own pace. Catherine spoke on her experiences with her own father’s ashes and the importance of splitting them among her family members as each person had their own ideas of what was the appropriate treatment of his remains. After she finished the

call, she turned to me to discuss her perspectives on the handling of the body. She believed that hospice “does a really good job of taking care of the patient” but fails to fully shift away once the patient dies. “At that point, we’re caring for the family, not the body.” She spoke of one situation where, when the hospice team arrived for the death visit, they found the patient’s wife lying in bed alongside her deceased husband. According to Catherine, the hospice team had disapproved of the woman holding on to the body and wanted it removed in a timely manner like usual. Instead, Catherine advocated for practices that involved interacting with the deceased, like grooming the body in the same way we often groom babies. Catherine’s outlook maintains a boundary between the living body and the dead one, yet encourages certain types of social engagement for the sake of the bereavement of the living. In her view, the hospice place can persist after death to serve the family, even when the patient is no longer the focus of care.

However, allowing the corpse to persist uncannily in place is also conceptualized as bad care by some. Though grounded in similar notions of care in hospice space, the chaplain Kalysta had differing opinions on leaving the body in the home. Though she emphasized the importance of helping families with the spatial transitions in death, she believed that the body should be removed within several hours. When I asked her about scenarios in which the family wished to keep the body around, she emphasized the importance of dignity.

There's a gap of time in which that body has to be picked up...Because that is not right by that person who just died. It's disrespectful. The body is slowly breaking down anyway.

In Kalysta’s view, hospice can preserve personhood by displacing the body from the home before physical decay can sever identity from appearance. She asserts that grief care can occur in other spaces: “We have to treat this person with greatest respect, because you can go to the funeral home after that.” In essence, the hospice place’s final purpose is to deconstruct itself.

“Call Amicus First”

Variations on “Call Amicus First” were plastered over nearly all of the materials given to caretakers of hospice patients. The intake packet even included a large phone-shaped fridge magnet to display in the home. Caretakers were instructed to phone the 24-hour on-call nurse as soon as the death occurred so that proper arrangements could be made. However, for the final death discussed at one IDG meeting, no call was made to Amicus when the patient died. Instead, the death was discovered by Kalysta, who traveled to the patient’s residence for scheduled spiritual care. That morning, she had called the patient’s daughter for permission to arrange the visit. However, the woman spoke primarily Spanish, so Kalysta was not certain that the daughter fully understood the situation. [This is what she said]

And I go there, and I'm knocking the door. And there's nobody, and I just look around. And there are other cars. And then, I saw one guy with the flowers. Then, I said, ‘Hey, are you coming to visit [the patient]? Is this the house?’

He said, ‘Yes, yes, I have come.’

And I feel like there's some weird story, so I said, ‘OK, let me let me call the daughter, and she just told me about half an hour ago that I can come.’

And he said ‘Yes, yes, they are in the house. I also spoke to her.’ So, this is getting better.

He's on the phone talking to somebody; he says ‘we have to go around the back.’

And I said, ‘OK, so we go around the back.’ And the back door—there's like a bazillion people as soon as you open it. It's a small house, and there's like over thirty people in the house. And nobody tells me that she has died. Nobody’s saying anything; they're all looking like tearful. But then I, you know, I'm wondering, like is she actively dying? Has she gone? Like what is going on? What is happening? Nobody says jack. So anyway, it's a small room which is probably this size with the furniture and the people and the children walking around.

Kalysta waved her arms to gesture to the Amicus office we were sitting in. Though the room was probably built as a one-person office, the furniture was arranged to fit two back-to-back desks and a tall filing cabinet. The room would have felt overcrowded with five people—fitting a full family gathering seemed impossible.

Then, you go through this really small kitchen which it's like maybe 3/4 of the size—maybe it seemed like that because of all the, you know, oven and whatever—and so then, there's another. There's a bedroom that's a little bit bigger than this [room]. The bed's in the middle, and they're over there. And there's people over here, and they're all saying the rosary and stuff. So, I was raised Catholic. Went to convent school—I'm quite familiar with Catholic practice. And they're just saying the rosary, and there's one person leading like—it looked like a novena in action. And so I said, 'Who is that? Like, who's the daughter?' I see all these women and the people like, just like what's going on?

...And they say, 'Oh yes, yes, this is the daughter.'

...So I said 'Oh, you know, thank you for letting me come, and I wanted to talk to you about your mom.'

She says 'Oh no, this is not a good time' and I'm like, this is changing.

So I said, 'But can I see your mom?' Because I'm thinking I've come all this way, at least if I could lay eyes on her. And literally we're standing right by the bed anyway, so I'm like 'Oh, is she okay?' So when I put my hand on the mom's hand, she was ice cold. And I saw her, her color was not as somebody who was actively dying or just died. She has died. Like a while ago. I was like, I don't know what's going on.

After discovering that the patient had been dead for some time, Kalysta quickly called up the Amicus office. When the chaplain asked the group why they had not called themselves, the flower-carrying man explained that they "had to do the rosary first." She suspected that the family had "probably put ice under the bed" to preserve the body, which she speculated had lain there for fifteen hours. There may have been a miscommunication about the death procedure (written materials, in particular, are often English-only). Or the family may have just decided that they were not yet ready for the body to pass into the hands of medical authorities.

Regardless, this scenario demonstrates how the hospice space constructed translocally by care staff can be distant from local understandings of place and care.

Kalysta's retelling of this experience stands out as both tactile and spatially concerned. When I spoke with staff members, they often understood that I had a good degree of familiarity with hospice—exemplified by the frequent use of “you know” as an interjection. As a result, in descriptions of the hospice care space, the expected was likely to go unsaid while the unexpected received particular attention. Home hospice is primarily imagined as a space for dying, while proper funerary rituals are localized to an off-site cemetery and funeral home. In emphasizing the claustrophobia of each room, Kalysta constructs a place where the grieving crowd does not ‘fit.’ The attempts to create a hospice place were also contested by the space's unknowability to hospice staff. The environment did not give up information easily. The unanswered front door and the series of crowded rooms obscured the patient from the chaplain's view. The language barrier made information even more inaccessible, and—as Kalysta repeatedly emphasized—even the few people who spoke English did not tell her about the patient. It was only when she physically and visually engaged with the body that she learned of the death. At this moment, Kalysta came in visceral contact with the uncanny. The gesture of the chaplain touching hands with the patient was an act intended for the spiritual care of the living in hospice place. Instead, she is confronted with the ice-cold touch of a body that is decidedly unexpected and out-of-place in-home hospice.

Hospice is many places

The COVID-19 pandemic has increased interest in remote or home-based care across medical disciplines. Within Amicus, nurses noted that more people began taking care of their relatives to

keep them close during the crisis. In this changing medical landscape, it is more important than ever to understand how care places are made outside the clinic. Though the home hospice space may have been created translocally by Federal efforts to divest in the dying, hospice staff engage in placemaking efforts intended to care for the personhood of the patient. In navigating shifting dimensions of safety, independence, and authority, care workers try to build an environment that recognizes its inhabitants as whole and valuable. This ethic of care explains the decision to work from a “safety care plan” instead of a “smoking cessation care plan” in the opening vignette. However, local processes of meaning-making in the home do not always align with philosophies of good care. In particular, the uncanny space created by the dead body in the home complicated the temporal life of hospice places. The contested goals of hospice care map onto the diversity of dying experiences to create endless permutations of the hospice place. Though Amicus hospice is not a place, it enacts care through making many places.

Section 3: “A normal and common physiological response to loss”

Bereavement care was at the heart of my work as an Amicus volunteer. Catherine and I crowded into her office each morning to attend to the day’s work. I would pull over a rolling chair from the meeting room and set up a black plastic folding desk on the carpet. Catherine’s desk was always piled high with spare papers and sticky notes, which I brushed aside to make room for my laptop. She often welcomed me by reporting the number of newly deceased: “We had three deaths last night.” Then, I would pull out my papers and get to work on bereavement tasks for the day. The care of bereaved family members was justified through the holistic “unit of care” model, which recognizes death as an interconnected process that affects the entire kinship system. The Amicus volunteer manual reads “Patients, their families, and their loved ones are the unit of care.” As hospice philosophy expanded the boundaries of who qualifies as a care recipient, the structures intended to evaluate that care also expanded. These systems form a kaleidoscope of interactions: ensuring care, limiting care, and building new forms of care altogether.

Bereavement Services

Each newly bereaved person was the responsibility of Bereavement Services. The team consisted of Catherine and several volunteers, with occasional assistance from other employees. The social worker identified each person who might require grief care on the “Grief Risk Assessment” medical record. Next to their name and address, the social worker would record their relation to the patient: family members, friends, partners, or even long-term professional caregivers. Bereavement care was also recorded through a “care plan.” Over the course of

hospice care, various care plans would be “opened” in the electronic medical records to represent the various physical, situational, and psychological challenges that care staff were working on with the patient (the “smoking care plan” and “safety care plan” mentioned in section two are just a few of many examples). A care plan was “closed” in the records if the challenge was overcome or the patient died. After death, we opened up a bereavement care plan for each bereaved person within the patient’s file—placing bereavement care in parallel to the medical goals of hospice care. In the days following the patient’s death, we mailed each person three paper materials enclosed in two envelopes: a printed “introductory letter” explaining bereavement care, a hand-written “sympathy card” expressing condolences for the loss, and the newly-bereaved edition of the *Journeys* newsletter offering advice on the early stages of grief. Each component was photographed and uploaded into the patient’s medical chart—ready for the auditor’s review, as Catherine would often remind me.

After a few days, we called each person to check in on their emotional state and ask if they would like to receive bereavement services. The details of that call too were recorded in the patient chart as a “progress note.” We made additional calls at three, six, and thirteen months before “discharging” the bereaved. Those on one side of the state border would also be offered a home bereavement visit in an effort to comply with regulations. However, the neighboring state regulations did not require these visits, so we did not offer them. When we decided to discharge the bereaved, we mailed a “discharge letter” and filled out a “discharge summary” in the chart detailing the success of grief support. The chart offered a series of checkboxes to indicate what “goals” had been met through hospice bereavement, recording both symbolic care acts (“supportive phone calls” or “grief education materials”) and indicators that the bereaved was re-

engaging in normal life behaviors. Finally, we would close the bereavement care plan in the medical records, signaling that the challenges of grief had been appropriately cared for.

Outside of hospice, grief care is a common informal practice in the wake of death. Many of the care methods employed in Amicus Bereavement Services strive to replicate this interpersonal care in an institutional context. However, though the methods of treatment may not have been explicitly biomedical, the reality of day-to-day bereavement activities are crafted in the footprint of existing biomedical systems. As discussed in section one, hospice is primarily funded by Medicare—and therefore, must prove its efficacy to the state to be seen as deserving of support. In the economic logic of federal medical insurance systems, payment must result in care, and that care must be observable by the state. Since hospice is classified as an extension of biomedical healthcare systems, it has adopted the same models of self-surveillance through medical records. The institutionalization of medical records has a dramatic effect on the landscape of care, especially in the case of care processes that are primarily interpersonal.

The biomedicalization of bereavement care was most apparent in the adoption of biomedical linguistic patterns to describe the bereaved. The person's grief "risk" was "assessed" before care begins. The care was temporally bounded through the "opening" and "closing" of a care plan, at the end of which the bereaved would be "discharged." Much like caring for a diseased body, bereavement services imagined care as "progress" towards the "goals" of a healthy ideal. The check-box medical records also privileged a uniformity that imagined the bereaved as nearly identical subjects. Medical knowledge often prizes replicability and generalizability of methods. For care to be assessed as effective (and identified as care at all), it must be confined to specific knowable categories. The vast majority of the mailings we sent out to the bereaved were identical, and even the handwritten cards often followed a template. The

frequency and nature of bereavement calls and visits were on a set schedule. When she encountered a particularly distressed person, Catherine would schedule extra visits and offer her phone number for support. Overtaken with empathy for the bereaved, she would stretch herself thin by making calls at all hours of the night. However, realistically, there was not enough time or personnel to offer as much individualized care as she would've liked. Catherine was almost constantly overburdened, and bereavement volunteers often found themselves facing an extensive backlog of calls. Many days, more time was spent recording the fact that care had been provided than actually providing care. Perhaps more concerning, Bereavement Services had to privilege care that was observable by institutions over the individual needs of the bereaved.

One day, when Catherine had left the office to run errands, I took up residence in her office. She had asked me to handle a long list of overdue bereavement discharges, and I was slowly making my way down the sheet. For each entry, we were required to call the bereaved to inform them of the discharge before mailing a letter notice. Before calling, I often flipped through the medical records to get an idea of each person's story. Catherine, the social workers, and the chaplains recorded notes on everything from family tensions to personal hobbies. As I searched the record for the next name on my list, I opened up the most recent progress note: a bereavement call by Catherine from six months ago. The conversation had been short, and the chart noted that the bereaved daughter had requested that Amicus stop sending the monthly *Journeys* grief newsletters. Every time they arrived in her mailbox, she was reminded of her grief, and it brought her down the entire day. I feared that another phone call might have the same effect. But the woman had not yet requested a full discharge, so I had no choice but to reach out for a final check-in. I dialed her number into the company phone and waited, hoping the tone would go to voicemail. Instead, she picked up. I sped through my spiel explaining the

discharge, skipping over my usual attempts to open up into more in-depth conversation. She answered each of my questions with curt, single-word responses. Within a minute, I had finished the call and got to work filling her discharge documentation for the medical records. At times, the effort to create proof of care comes at the expense of the subject of care. In this case, the daughter's psychological distress at the phone call could be seen as a necessary consequence of care through surveillance for pathological grief.

Pathological grief

One of Catherine's primary responsibilities involved traveling out into the greater community as a "hospice ambassador." She often sent out requests to local schools or community centers, hoping to help people warm up to the idea of end-of-life care. She once confided in me that, given the choice, she would make this ambassador work her "whole job," instead of "this crap," waving dismissively at the medical records she was updating. Her personal views on hospice aligned closely with the hospice philosophies outlined in section one. From her perspective, general discomfort with death pervades American society, hindering us from preparing adequately for grief or end-of-life care. The ways that she taught about grief in the community engaged the tension between institutional effort to map grief onto an illness model and death-positive philosophies of grief normalization.

One afternoon, I drove out to an assisted living facility to assist in one of Catherine's grief education sessions. I parked my car next to the street curb and stepped out onto the well-manicured lawn. I was greeted by parallel rows of identical single-story houses with white picket fences adorning each corner. I made my way to an apartment building at the end of the road, where the session was taking place in a small chapel. The room was plainly decorated, except for

a large, cross-adorned stained-glass plate hanging from the center wall. A few older adults shuffled into the first few rows of chairs, but most seats remained vacant. When commenting on the small size of the gathered group, a woman remarked that people may have been reluctant to attend since the topic “hits too close to home.” Catherine thanked the small audience before her for attending and launched into her presentation about grief.

“When someone is grieving, we hand them a handkerchief and tell them to ‘stop crying.’ Why are we not comfortable with tears?” Catherine began her presentation by insisting “I’m on a one-woman mission to change that language.” She went on to define grief as “a normal and common physiological response to loss.” The idea of normalization ran throughout Catherine’s ethos of bereavement. She frequently drew on biomedical phenomena as support for the “normality” of grief. She described “STERBs” (short-term energy-relieving behaviors) as “the brain’s way of coping with trauma and grief” and pointed to other “bodily, physiological responses” such as dietary changes. By framing grief as “physiology,” Catherine drew from hierarchies of knowledge that emphasize biomedical conceptions of the person. Grief is confined to the individual and takes on a fleshy realness. Using an acronym like “STERB” speaks to a body of shared professional knowledge, as is exceedingly common in biomedical contexts. All of these explanations work to represent “normal” grief as both pathological and expected under biomedical frameworks. However, Catherine also assured her audience that grief does not require a clinical diagnosis and is not the same as clinical depression. This assertion distances grief from more stigmatized pathology, furthering its universality. As the presentation went on, the audience began to grow increasingly more comfortable. As they began to share their own experiences, Catherine’s words seemed to resonate with them.

Catherine described “mourning” and “grief” as representing “different and complete parts” that “go hand in hand.” She differentiated mourning as outward expressions of grief, such as crying or funerary rituals. She reassured the audience that mourning is “a healthy part of bereavement” meant to make us “hopeful and happy” about returning to daily life. “There is no right or wrong way to grieve” she insisted. She explained the Kübler-Ross model to the crowd, then called me and a few other volunteers to the front of the room. She handed us each a paper sign inscribed with one of the Kubler-Ross stages of grief: denial, anger, bargaining, depression, and acceptance. Once we had arranged ourselves in order of the stages, Catherine turned to address the crowd. Though this might be a common way to describe grief, she explained, everyone’s grief journey looks different. She then told us to rearrange our signs in new formations, having some of us step in and out of line depending on the scenario she described. She reassured the crowd that everyone may experience the stages in a different order, and some may skip a section, repeat a step, or experience an entirely different stage altogether. One audience member mentions “fear” as a possible stage of grief not covered in the Kübler-Ross model. “Yeah, sometimes grief can be masked as fear,” Catherine replies. She referenced a quote from C.S. Lewis, which she remembered as “I never thought that grief would feel so much like fear.”

Despite encouraging them to accept all paths through grief, she warned the audience to beware of “complicated” or “pathological” grief. She pointed to signs associated with “not resuming regular activities,” including self-harm, withdrawing from religious activities, or not getting out of bed. Framing particularly damaging grief as “pathological” could be viewed as an act of care by Amicus staff. However, grief is inherently disruptive to normal modes of existence. Catherine admitted that some days it is okay to “just get up and turn the television on”

when the grief is overwhelming. She encouraged the audience to not avoid grief “in order to protect ourselves from those thoughts and feelings” because “we’re doing ourselves a disservice.” Drawing the line between pathological and normal grief is treacherous, especially in a care philosophy that prioritizes the normalization of grief. Attempts to formalize this delineation have pervaded Amicus hospice through the process of assessing grief risk.

Risk and grief

When a patient first entered Amicus hospice services, a social worker would complete a Grief Risk Assessment for their family, caretakers, and loved ones. As members of the bereavement department, we were responsible for creating a new bereavement risk assessment two months after opening a bereavement care plan. Each person is assessed according to checkboxes for particular risk factors, then ranked for the severity of grief risk on a scale from one to six. Some identified risk factors were more situational, existing regardless of the bereaved’s express emotional state: “age less than 18,” “dependent family members/children living in patient’s home,” “concurrent life crisis,” multiple or recent losses,” and “death means loss of constant companion or emotional support.” Other risk factors required the hospice staff member to make judgments about the bereaved’s handling of grief: “unable to share feelings,” “difficulty making decisions,” “inflexible thinking,” “inadequate or negative coping skills,” “unprepared for death/strong denial prior to death,” “difficulty coping with past losses,” and “unresolved grief from prior losses.” With all bereaved (and their care) organized under the patient’s file, hospice implicitly recognized grief as a phenomenon that exists not only within people but between them. By far the most common risk factor identified by the social workers

was “death means a change or loss of role or function.” According to these risk assessments, grief was also characterized by a shifting of social and environmental positioning.

These gray areas in how social workers and bereavement staff characterized “risk” reveal framings of pathological grief. The risk factor “cultural issues present” left room for possibly troubling implications about grieving practices that deviate from culturally dominant scripts. One of the oft-repeated goals of the “death positive” movement was to normalize grief.

“Normalization” often encouraged making grief a more prominent facet of public life and accepting that grief could look “different for everyone.” However, the biomedical model follows a script where an issue must first be pathologized to be cared for. In fact, diagnosis—the process of pathological recognition—is often considered an act of care in and of itself. In typical biomedical fashion, the two bereavement risk assessments (along with other medical records) were examined by auditors as proof that Bereavement Services was providing adequate care. These risk assessments allowed for staff to share information between teams and divide resources for “high-risk” bereaved. However, they also required staff to make distinctions on what was and was not acceptable grief. Consequently, one of the lines I often found myself reading (or writing) as I would work through patient files was “bereaved is grieving appropriately.”

“Complicated” calls

Though most official forms of bereavement care begin before the patient’s death, grief care often occurred throughout a patient’s time on service. Sometimes, this includes attending to anticipatory grief for those who were particularly stricken by the impending loss. However, in many cases, this involved more subtle care aimed at preparing people for a world without their

loved ones. One morning, Catherine and I were elbow-deep in the supply closet, gathering supplies for the nurse visits that day. As Catherine stretched her arm to pull a bag of underpads off the top shelf, she was reminded of a veteran ceremony she had attended for a patient the previous week. “I took a picture of the veteran and all the other service members,” she told me. “But when I looked at it when I got home, I saw he had a pad sticking out beneath him! I couldn’t let his mom see him like that, so I photoshopped it out.” She explained that she had also moved his walker out of the way and cropped it out, leaving just the patient and the two service members holding a folded flag. When I asked about her reasons, Catherine said that it was “all about preserving dignity.” She wanted to preserve his memory for his family because “pictures are all we have left.” “Preserving dignity” through obscuring the technological symbols of illness (the walker or pad) speaks to the impacts illness and ability have on personhood. However, the object of care of “preserving dignity” is not the (living) patient themselves, but rather the memory that lives on in their loved ones. This demonstrates how identity and objects of care are diffuse over time and social structures.

The nature of familial care can lead to a blending of the categories of “patient” and “bereaved.” Sometimes, ensuring a caretaker has adequate support and resources was essential to patient care. Other times, more than one person from the same social group would come under Amicus’s care, often spouses or life partners. The death of kin was a common feature in the narratives of many dying patients, especially older ones. While I was discharging the daughter of a patient, Catherine poked her head into the office upon hearing his name. “A really sad story,” she told us. Sometime earlier, the patient’s wife had been under Amicus’s care until her death. He and his wife had shared a room in the nursing home, so the staff had the chance to get to know both of them. However, once his wife died, he became convinced that she had left him for

another man. He entered Amicus's service himself soon after and lived out his final days angry and agitated. To help offer emotional support, volunteers brought chalkboards so they could communicate with the deaf man. Catherine sighed, "Honestly, I was glad when he died; this world was not a kind place for him." "Not related to the discharge," she admitted, "just wanted to tell you the story."

One morning, Catherine and I were sitting around in the office commiserating over our mutual exhaustion. She confessed that she had several "complicated" bereavement calls the previous day and was dreading the list of new calls that sat in front of her. One of those "complicated" calls had been from a man whose wife had died two months earlier. Catherine said he "could barely function," only able to say a few words between gasping breaths as he cried. She said that she had made a "verbal contract" with him to go visit his general practitioner to get more professional help with his grief. Apparently, he had already made and subsequently canceled the appointment multiple times in the past. She seemed hesitantly hopeful that this time, he might actually go—but admitted she had few other ways of intervening. The other "complicated" call was to schedule a visit with a patient and his wife to help with anticipatory grief. The couple had been married 72 years and were in what Catherine described as "strong denial" of the husband's impending death. In what she saw as a downstream effect of this denial, the couple had begun fighting nonstop—exhausting the nurses and social workers who had to make near-daily trips. Catherine said that it was a "shame" that they were spending their final time together fighting over "such little things" instead of accepting reality. "I mean, he's 92," she said. She hoped that making adequate preparations for death should be a natural facet of that stage of life.

As it turned out, Catherine's fears of more "complicated" calls that day would be realized. While I was unpacking nursing supplies in the central hall, she had closed the door to her office (as she often did when she was concerned a call might require privacy). After a long while, she pushed open the door and let me back into her office. She had just finished talking to a newly bereaved man who had just lost his wife. Catherine described him as "agitated" with a solemn look on her face. He had told her "I never should've let her go on hospice" and "when she stopped breathing, y'all didn't do anything." She mimicked her response "Sir, she had a DNR" and explained that "in grief, we may find ourselves thinking about all the things we wish we could've done differently." We decided to discharge him from bereavement services without an additional letter or call in order to not agitate him further. Though Catherine seemed to disagree with his reasons for regretting hospice, she had empathy for the way grief drove his anger.

Grieving together

As Catherine wrapped up her presentation, she began to field questions from the audience. The first few questions were fairly straightforward, with an arms-length separation achieved by talking about death in generalities. One person requested tips on how to converse with a dying person, while another woman asked about the stigma associated with grieving a person who had been dying for a while. But as the ice began to break, more participants began to share personal details of their struggles with grief. The feeling of the meeting shifted from a presentation to something more akin to a group counseling session. Though none of us moved from our chairs, over time, everyone seemed to turn away from the altar where Catherine stood

to face each other. As the conversation became more emotional, I put away my notebook to be more present with everyone's grief.

Even more than hospice services for a dying patient, grief care evokes the social and emotional dimensions of care. It exposes the tensions between the humanistic ideals of the hospice movement and the institutional structures of healthcare it works within. Most notably, the need to identify pathological grief sits in direct opposition to the desire to normalize it. Despite and within these contradictions, Catherine, volunteers, and other staff found ways to care for individual people and societal grief as a whole—primarily through acknowledging grief as an intersubjective phenomenon. This could mean caring for a kinship structure as a whole or simply viewing the connection between the bereaved and staff as care in itself.

Conclusion

Since its inception, the hospice movement has sought to change how the healthcare system—and American society—approaches dying. Sixty years after the movement's beginning, I observed many of these humanistic ideals in Amicus Hospice's practice. They sought to preserve dignity in death by emphasizing individual personhood. This care of personhood spans from respect for individual choices to witnessing of patient histories. The hospice philosophy places a major emphasis on a more diffuse "unit of care," which brings webs of kinship into the care effort. These care efforts can include attention to the kin themselves so bereavement services or social support. All of these actions speak to the recognition of dying as more than a purely biomedical event occurring in an individual patient. The hospice movement has long made an effort to paint itself in contrast to traditional biomedical institutions and practices. However, hospice's increasing integration into biomedical systems of authority changes the landscape of how (and if) these ideals are carried out in practice.

Hospice arose in the late 1960s as a kind of "counter-institution," to address perceived failures in the hospital system's tendency to neglect dying patients. Since that time, financial and political pressures have drawn hospice closer to the biomedical system. In particular, the promise of Medicare funding comes tied to a system of regulation and institutional surveillance. Many have questioned the degree to which this institutionalization has caused hospice to compromise its ideals in favor of the very systems it had set out to replace. Others have questioned the seemingly natural assumption that professional institutions (whether they be counter-institutions or not) are the appropriate center of authority for death and dying. Though I certainly had these more cynical questions in mind as I approached my ethnography, I chose to focus my research

instead on the perspectives of the hospice staff charged with navigating these systems. Through my work at Amicus, I learned where these staff locate care and the role of hospice in dying. Some hospice nurses saw their position as an opportunity to bargain between biomedical authorities and the desires of a dying patient and their kin. Many saw the ways independent decision-making could restore personhood. Further, the complex navigation of authorities in physical space also lends itself to the creation of new relationships with institutions. Fulfilling the desire to die at home (or, at the very least, outside of a hospital) was about more than physical location, but was an opportunity to care through the creation of a hospice place. Hospice staff worked toward this particular sense of good death by moving towards ideals of harmonious kinship relationships and respecting certain authorities of home as outside the reach of the biomedical.

Emotional and spiritual care have become officially codified components of the hospice system. This allows staff to dedicate more of their time and resources to these forms of care and also serves as an institutional recognition of the importance of holistic care to dying. However, in the name of ensuring such care is delivered (largely under Medicare regulation), surveillance through medical records and documentation is required. These regulations molded care delivery into a more measurable and documentable form, instead of focusing on the interpersonal roots of these care ethics. It also changed how patients and the bereaved were viewed, by using frameworks like “pathological grief” that occasionally ran counter to narratives promoted by the hospice movement. Though their actions were restrained by these demands (often simply by the time necessitated to complete them), Amicus staff also worked to find ways to work beyond them through forming relationships with the bereaved.

The growth of the aging population in the United States means that the ubiquity of hospice is likely to grow even further. Though I believe future research should examine the many other possibilities for addressing the need for end-of-life care beyond traditional hospice, it is well worth taking a closer look at the ways hospice care is implemented. Hospice's strengths in kinship, emotional, and spiritual care may have valuable applicability in other areas of healthcare. In studying the views of hospice staff, I hope that this thesis can give us a better picture of how the ideals of hospice care are put into practice. However, hospice in its present form is bounded by institutional constraints that can limit the possible forms of care. This work draws attention to not only the effects of institutionalization on hospice care but also to the strategies Amicus staff use to navigate these challenges to achieve good care at the end of life. The understandings of placemaking, grief care, and identity-formation developed through this work can be used to build a future for hospice care.

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