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EXPANDING BEYOND BIOMEDICINE: HOW HOSPICE PROVIDES WHOLE PERSON CARE

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Abstract

This work is an exploration of how patient-family units navigate and experience hospice care. Since its introduction to the US, hospice care has been transformed from a social movement to a Medicare benefit. Through the Medicare Hospice Benefit hospice organizations now can be finically viable businesses. As hospice care has evolved it has become a form of care that is rooted in biomedicine but extends beyond the confines of biomedicine to provide better care to dying patients. Through affective care and a holistic approach, hospice care provides patient-family units with personhood care and opportunities for whole person healing. Hospice care is medical care that prioritizes relationships and the patient-family unit's needs. While hospice care is imperfect, it can be used as a model for how to improve biomedical health care systems.

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The End of Life Through Hospice Care

I met Valerie Stone when I first began volunteering for a hospice organization in Norman Oklahoma which I will call Heritage Care Hospice. Mrs. Stone was a small, gentle woman who I enjoyed talking to because of her joyful nature. I would visit Mrs. Stone every two weeks during lunch time and talk to her and the other women at her table about faith, the weather, and their life histories. About two months after I met Mrs. Stone, she had a fall which caused a quick and severe decline in her health. When I visited her shortly after the fall, she sat and talked to me but often stopped to grimace in pain or took a while to respond to my questions. During this visit she explained to me what had happened and thanked me for coming to see her and getting to know her. I understood that she was saying her goodbye to me that day, and a week later I received a message that Mrs. Stone was in a comatose state and would soon pass away. As her companionship volunteer, I was asked to go and sit with her for a short time so she would not be alone. On our last visit Mrs. Stone was sleeping, wrapped in blankets, and tucked into her bed with a stuffed animal. I pulled up a chair beside her bed unsure of how long I would be able to sit by her side without getting too upset or disturbed. I began to share updates about my life and things I had done or planned on doing that week. As I talked, Mrs. Stone lay completely still. The only indication that she was still alive was her slow breathing. Even with the unusually slowed breathing, Mrs. Stone appeared peaceful to me. She had been made physically comfortable by pain relieving medications and other comforts such as her blankets and stuffed animal, and she was not grimacing in pain like she had done when I talked to her last. While I will never know how Mrs. Stone experienced those last few days, her body seemed to be more at ease than it had been the last few weeks I knew her. Before leaving that day, I said my goodbye to Mrs. Stone

and thanked her for the opportunity to know her. Within a week Mrs. Stone peacefully passed while sleeping.

Mrs. Stone was one of the first individuals I knew who passed away while using hospice care. While I only visited her for about three months, her death opened my eyes to what a death through hospice care could look like. Heritage Care Hospice responded quickly to Mrs. Stone's fall and provided her with pain management treatments that allowed her to sleep peacefully until her body was able to let go. Heritage Care Hospice went beyond the expected pain management practices and did their best to ensure that someone was with Mrs. Stone during her last few days so that she would not die alone. Mrs. Stone's death began to illuminate for me the desire of hospice organizations to care for the whole well-being of the person, instead of only treating the physical ailments of their patients. Without the care of hospice, Mrs. Stone's death could have been characterized by intense pain and loneliness. Hospice care was critical to the peaceful death that Mrs. Stone was able to experience.

Mrs. Stone's death highlights the benefits of using hospice care during the end of life. She received pain management medications, daily care when she was actively dying, and was connected to a care team that could provide her resources for navigating the end of life. The limited time that I was able to spend with Mrs. Stone provided a glimpse of what hospice care was like for a patient. While I was present during Mrs. Stone's active dying period, I was not privy to some of the confusion and difficulty that often accompanies hospice care. Each patient-family unit's experience in hospice care is unique and is influenced by the structures of society that they move in and out of. Through this research I wanted to understand how individuals navigate the structure of hospice and how hospice care affects the experience of the end of life. The experiences of my interlocuters highlight the complexities of navigating hospice care and

the importance of hospice care's approach to the end of life on health care. Through their experiences I came to understand hospice care as a model for how medicine can provide quality relational care to their patients.

End-of-life care is becoming increasing important as the baby boomers continue to age. According to the Aging Our Way plan from the state of Oklahoma, by 2034 the number of Oklahomans who are 65 years or older will be more than the population of individuals who are 18 or younger (Aging Our Way, 2024). This state trend is occurring across the nation as the baby boomers move into the end-of-life period. Standard end-of-life care often involves extended hospital stays and life-prolonging care acts that do not always result in a more enjoyable end-of-life experience. While standard end-of-life care is important and is desired by some patients, it is no longer the only acceptable form of death care. Hospice care has become increasingly popular for its commitment to providing biomedical care that ensures the patient's comfort throughout their end-of-life period.

Hospice care organizations' commitment to comfort care over life-prolonging care can make it appear to be a less complex health care system. While hospice care is not dealing with the complexities that come with life-prolonging care, it has its own difficulties and tensions that make it a complex form of health care that patients have to learn to navigate. Hospice care is a form of medical care that combines standard biomedical care and holistic care practices. Hospice care requires physicians and nurses to be educated and trained as all biomedical care providers are. They understand the body and its ailments through biology and understand how to treat patients' needs with medication. While hospice is rooted in biomedical care it does not pursue the extension of life through advanced medical technologies. Hospice care professionals approach their patients through a holistic perspective that seeks to treat the whole person and

their family members instead prioritizing the disease trajectory. Within hospice care there is a tension between being both a form of biomedical care and holistic care. This tension produces a form of care that extends beyond what biomedical care can provide during the end of life.

Hospice care originated in London during 1967 as a social movement against the inadequate care provided for dying patients where volunteers provided the care that patients needed. As hospice organizations have developed, hospice has become both a form of health care and a business opportunity. Hospice organizations must balance proving personalized care with the necessity of making money from that care. This tension creates confusion and gaps in understanding for patient-family units which makes hospice more difficult to navigate. While hospice does not always balance these responsibilities perfectly it is a model for how to extend care beyond the limits of biomedicine while continuing to be a viable business.

Anthropological Perspectives on Biomedical Care

Biomedical care is the standard care that is provided in most health care institutions in America. Biomedical care has produced incredible advancements in our understanding of the body and how to prolong life. Biomedical care attempts to improve the quality of patients' lives but can fall short of this goal because of its commitment to prolonging life. Sharon Kaufman explores how hospitals create prolonged deaths in her ethnography *...And a Time To Die.* Kaufman explains that lifesaving interventions create a "gray zone" between life and death where people are kept alive, but not able to live their lives as they desire (Kaufman, 2005: 1). Kaufman explains that hospitals are structured to provide biomedical care that is focused on saving and extending lives until that goal is no longer possible. The difficulty of knowing when someone is going to die and the commitment to life-prolonging care results in unsatisfying deaths for the patient and their family (Kaufman, 2005). Kaufman's "gray zone" highlights the

need for a different kind of care structure during the end of life. Hospitals do their best to provide people with quality care that meets their needs, however the structure of hospitals prevents physicians and nurses from providing the kind of comfort care that more people are seeking during the end of life. Kaufman's ethnography points to the need for biomedical care to accept that prolonging life is not always the answer. Sometimes what a patient wants and needs is comfort and pain relief instead of physical healing. Kaufman's work illustrates why hospice care is growing increasingly important.

Medical anthropologists have long argued for a change in biomedical care that would produce better outcomes for patients. Nancy Scheper-Hughes and Deborah Gordon provide critical analyses of biomedicine's faults and how it can evolve to better provide for people's needs. Nancy Scheper-Hughes establishes a groundwork for how to conduct critical medical anthropology. She urges medical anthropologists to explain the complexities of medical care and to explore non-biological forms of healing (Scheper-Hughes, 1990). Scheper-Hughes is inviting anthropologists to expand their understanding of medicine beyond the physical condition of the patient to the whole well-being of the individual and their position within the world. Scheper-Hughes' challenge is for anthropologists to see and understand how medicine can go beyond where it is now.

Medical care is constantly evolving but has rooted itself in biomedical care practices. Biomedical care uses knowledge of biology to create technologies and treatments that prolong life. Deborah Gordon illuminates the logics behind biomedical care in her chapter "Tenacious Assumptions in Western Medicine." She explains that biomedicine "constitutes and is constituted by society," however it claims to be separate from society and universal (Gordon, 1988:19). Biomedicine understands sickness and disease as something that naturally occurs and something

that can be separated from the individual that it inhabits. Biomedicine claims to be separate from nature with the ability to overcome natural events such as disease and death (Gordon, 1988). Through the knowledge of biology, biomedicine has developed techniques, practices, and technology that prolong life and transform the way that we die. Gordon encourages anthropologists to understand the logics behind biomedicine and how those logics inform the patient's experience of care. Both Scheper-Hughes and Gordon pull back the curtain on how biomedicine functions and where its faults are. As Gordon explains, biomedicine is not distinct from society but is informed by the people that it serves. For medical care to provide better experiences of care, biomedicine must expand beyond its current boundaries and understand how society impacts its practices.

Thinking about Scheper-Hughes' and Gordon's analyses, many medical anthropologists have conducted research that studies the social factors connected to health. In recent years anthropologists Seth Holmes has continued building upon previous scholars' ideas. In a lecture to the UC Riverside School of Medicine Seth Holmes suggests that we need to "expand the frame" of what we are looking at to better understand how people develop disease and experience death (Holmes, 2019). Holmes explains that to properly serve people medicine must look beyond what is easy to see and understand the structures that people interact and how that alters their experience of health and health care. While Holmes was talking to medical professionals, the need to expand the frame applies to anthropologists as well. To truly understand individuals' experiences of hospice care, the structures that patient-family units interact with must be explored. Hospice care has two main structures that dictate its functioning: biomedical care practices and the Medicare Hospice Benefit. Biomedicine is critical to hospice care as it provides the medical knowledge of how death occurs and how to medically treat patients to create comfort

while dying. The Medicare Hospice Benefit provides hospice organizations with patients and revenue. The importance and influence of these two structures will be explored throughout the experiences of patients in hospice care detailed below.

Hospice Care

Palliative vs Hospice Care

To understand hospice care in its full complexity it must be distinguished from palliative care. The National Institutes of Health defines both palliative and hospice care as comfort care with a focus on the quality of life. In both forms of care service is provided by an interdisciplinary team and is not tied to a specific location. In some countries hospice care does not exist, however quality end-of-life care is still provided to individuals through palliative care. In these places, palliative care provides the services that hospice care would typically provide. In places where palliative and hospice care co-exist the difference between the two forms of care is found primarily in the timing of the care and the ability to seek cures (National Institutes of Health, 2021). To better understand how hospice and palliative care fit together anthropologist Mara Buchbinder explains palliative care as a spectrum; at one end of the spectrum a patient would receive both curative care and palliative care. At the other end of the spectrum would be forms of care that accept the inevitability of death and provide patients with the ability to actively engage in crafting their death. These forms of care could be things like Aid in Dying (Buchbinder, 2021). Within the spectrum of palliative care, hospice falls between life-prolonging care and Aid in Dying. Hospice care organizations and professionals acknowledge the inevitability of death and no longer seek curative care, while prioritizing the importance of comfort and choice in creating end-of-life experiences. The intention of palliative care is to

improve the quality of life of the individual and manage the physical and emotional symptoms that patients might face. Palliative care that is not hospice care typically begins with the diagnosis of a disease and accompanies treatments that are curative in nature (National Institute of Aging, 2021). When an individual chooses to not engage in, or ceases to receive life-prolonging treatment, they can enter hospice care. Hospice is a form of palliative care specifically designed for patients who have been given a 6-month life prognosis by a physician and who no longer desire curative treatments (National Institute of Aging, 2021). Hospice care is a more intensive form of palliative care in that it is available 24/7 and often manages higher levels of pain than non-hospice palliative care. The goals of hospice and palliative care are aligned in such a way that make it hard to separate non-hospice palliative care and hospice care, however they can be distinguished by their eligibility requirements and required patient services. The eligibility requirements and services provided by hospice care are more rigid and intense than non-hospice palliative care. As palliative care and hospice care have developed, hospice care has become a more intensive form of palliative care specifically for those who are experiencing the end of life.

The Origin of Hospice Care

The kind of hospice care that we have today is characterized by highly trained medical professionals that provide symptom relief through both standard medical practices and affective care. Hospice began as a social movement in response to the terrible deaths that were occurring in hospitals. In her ethnography of palliative care in the U.K., Julia Lawton explains that the hospice care movement was started in London's St Christopher's Hospice in 1967 by Cicely Saunders. Death within hospitals was impersonal and was seen by medical staff as a failure of medicine, which created deaths that were undignified and painful. Those who advocated for

hospice care chose to see death as a "normal and natural part of life" in which, care would focus on "quality rather and quantity of life" and include the needs of the dying individual's family members (Lawton, 2000: 12). Hospice care, as developed by Saunders, was a way to provide for all of the needs of the patient-family unit in the end-of-life period. Roi Livine, a sociologist studying palliative care, explained hospice as "a comprehensive philosophy of care that placed nursing at its center" (Livine, 2019: 36). At its core, hospice was an alternative way of providing medical care that results in more benefits for the patient-family unit.

The success of hospice care in the UK led to the rapid spread of hospice care to the United States, where it was first practiced by Florence Wald at Yale University as a pilot program. After the program ended, Wald established Hospice Inc. and began hosting conferences where she taught about providing hospice care. During this time, hospice began to establish itself as separate from other forms of care. The distinction between hospice care and other forms of medical care were finalized with the Medicare Hospice Benefit in 1982 (Livine, 2019). During the 1970's and 1980's leaders of the hospice care movement were wrestling with how to expand their services while not isolating themselves from the foundational values of hospice care. After the establishment of the Medicare Hospice Benefit, hospice was no longer a social movement but instead was solidified as an alternative form of medical care. Paul Torrens, a professor of health policy and management, explains that hospice care was placed between "the clinical world" which revolved around the patient, and the "financial" world that prioritized economics in health care (Torrens, 1986: 6). By the late 80's hospice care had developed from a social movement intent on providing quality care, to a form of medical care that had to wrestle with the financial viability of providing care to dying individuals.

Modern Hospice Care

Today the National Institutes of Health defines hospice as "an approach to care" (National Institutes of Health, 2021). While hospice care has changed since its introduction in the 1970's, it has retained its roots of being a form of care that acknowledges death and provides symptom management to the patient-family unit. The Hospice Foundation of America explains today's hospice care as "provid[ing] something more for patients when a cure is not an option." Modern hospice organizations are not hastening death but providing comfort (Hospice Foundation of America, 2024). In talking to Mrs. Rodgers, a nurse at Heritage Care Hospice, she explained hospice care as being "geared towards helping people transition to that next step in our existence…geared more towards comfort, teaching somebody what's gonna go on at that end of time and trying to teach their family so that they're not going into it blind and anxious." Mrs. Rodgers' explanation of hospice care and its ability to provide comfort and teach people is possible only because our understanding of the end of life has expanded.

In his ethnography of the end of life in Thailand, Scott Stonington explains that death is no longer a moment in time but instead is a period that is experienced (Stonington, 2011: 116). Stonington's insight reminds us that death is not a single moment, but is an entire period referred to as the end of life. When we begin to think about death as something more than a single moment, it becomes necessary to provide care during the entire end-of-life period. Hospice care seeks to provide care by recognizing when the end-of-life period begins, and when care is needed. Kaufman and Morgan highlight the importance of hospice care in their explanation that death is a social event that the living and the dying are engaged in (Kaufman and Morgan, 2005: 323). If death is a period that involves sociality, then the care that is given to the dying must include sociality. Modern hospice care seeks to be there for the patient-family unit throughout

the entire end-of-life period providing a level of care that is deeply social and ensures that patients and their families have their needs met.

Interdisciplinary Care Team Services

Hospice services are dispensed by an interdisciplinary team created for each patient-family unit. These services include medications and services for pain management, medical equipment, companionship volunteers, short-term respite or inpatient care, and grief support (Hospice Foundation of America, 2024). The interdisciplinary team is critical to providing all of the necessary and available services to patient-family units. Mrs. Tatum, the executive manager of two Heritage Care Hospice locations, explained the roles of each member of the care team. The registered nurses (RNs) are case managers and are in charge of the admission of patients. Licensed nurse practitioners (LPN's) are there to help the RN with their responsibilities. Mrs. Tatum explained that LPN's see the patients more frequently than the RN's. She described nurse aides as the "bread and butter" of the care that is provided. Aides typically visit their patients "three times a week" and help with "activities of daily living." The social workers are responsible for "financial resources, food, and medical equipment." Chaplains are an optional resource and provide "spiritual support." The hospice interdisciplinary team is comprised of professionals that can provide care for each aspect of a person's well-being. The RNs, LPNs, and nurse aides help take care of the physical body of the patient and do extensive work educating the patient-family unit. One Heritage Care Hospice nurse, Mrs. Wells, highlighted the importance of the education that the team dispenses. "We have to go in every visit and just re-educate, reiterate, and just let them know we are there for them." Mrs. Wells engages in physical care for the body of the dying patient while also informing the patient-family unit about end-of-life processes and the care she is providing. Each patient-family unit is assigned a social worker

who assists them in navigating the end-of-life period by setting up services that their patients need. The social worker can help the patient-family unit navigate hospice care effectively which allows them to focus on the affective and physical care received from other members of the care team. If so desired, the chaplain can help care for the spiritual, emotional, and mental needs of the patient-family unit. Through the interdisciplinary team, hospice provides care for the entire person and their family members. Mrs. Rodgers explained her work as a hospice nurse as "treat[ing] the whole family" because she is constantly in their homes and interacting with more than just the dying patient. Heritage Care Hospice's mission is to never let someone die alone. The care team seeks to be the support, education, and relief that is often not experienced outside of hospice care. Heritage Care hospice's staff live out their mission by being physically present with their patients, truly listening to their needs, and responding appropriately to the desires of the patient-family unit.

State Laws and Regulations for Oklahoma Hospice Organizations

Interdisciplinary hospice care services are coordinated and distributed through independent hospice care organizations. To legally provide hospice care in Oklahoma organizations must follow the Oklahoma Rights of the Terminally Ill Act and the Oklahoma Hospice Licensing Act. These acts ensure that patients and their families are given quality care that follows state approved care practices. The Oklahoma Rights of the Terminally Ill Act gives power to the patient to decide what their end-of-life treatment will look like. This bill was passed in 1992 and provides Oklahomans with the ability to make advanced directives and provides governance to uphold those advanced directives. This act outlines important provisions regarding advanced directives such as giving the individual patient the final say regarding their health care and the ability to request that life-sustaining treatment be withheld. Importantly, this act also

explicitly states that Aid in Dying, and euthanasia are illegal in Oklahoma (Oklahoma House of Representatives, 1992). While this act does not pertain directly to hospice care it gives patients the ability to make decisions about the end of their lives. Advanced directives can be used by hospice care providers to ensure that the patient's wishes are met to the best of their ability. This act also protects hospice organizations from legal prosecution if they stop providing life sustaining treatments upon the patient's wishes.

The Oklahoma Hospice Licensing Act, originally created in 1991, and amended in 2017, provides legislation on how a hospice organization can legally be established in Oklahoma. To get and maintain licensure, the organization must apply for the license each time it is up for renewal. The act requires hospice organizations to have a symptom control process, be available 24/7, and provide bereavement care. At a minimum the hospice organization must have a physician, registered nurse, social worker, and a counselor for their patients. The act also provides guidelines for how to file and respond to complaints and violations made against a hospice organization (Oklahoma Senate, 1991). This act ensures that hospice organizations are abiding by the legislation of the state and that they provide the minimum requirements as a hospice organization. While this act does not include any service requirements beyond what the Medicare hospice benefit requires, it creates a framework for how to establish and operate a hospice organization in Oklahoma.

Federal Requirements and Eligibility for Hospice Organizations

Hospice organizations in the U.S. must comply with both state regulation laws and the Medicare Hospice Benefit's eligibility requirements when enrolling new patients. For a Medicare beneficiary to qualify for an evaluation by a hospice organization they must have Medicare Part A insurance, have a certification of being terminally ill from a physician, accept comfort care,

and not pursue other treatments for their condition (Medicare.gov, n.d.). While some patients will enter hospice care without having Medicare, hospice organizations continue to follow the Medicare eligibility requirements and processes for those patients to ensure that they are always compliant with the strictest requirements. The enrollment process for Heritage Care Hospice was explained to me by the executive manager of two locations of the organization, Mrs. Tatum. She explained that after confirming a 6-month prognosis, the patient's physician will refer the patient to a hospice organization. After receiving the referral, the hospice organization will send a physician out to the patient's location to do a certification exam. If a potential patient seeks hospice care without the recommendation of their personal physician, the hospice care organization's physician will evaluate the potential patient to determine if they have a life prognosis of six months or less. The Hospice Foundation of America expands upon our understanding of what the eligibility assessment looks like. During this assessment the hospice physician will review the patient's medical record, do a physical exam, and establish the "psychosocial, emotional, and spiritual needs" of the patient-family unit (Hospice Foundation of America, 2024). If a patient is certified as having a 6-month life prognosis and agrees to receive comfort care instead of curative treatment, the hospice organization will create an interdisciplinary care team for the patient-family unit and begin coordinating care visits.

Positionality and Methods

Before experiencing hospice care I knew it only as a health care service for people who were dying. I believed hospice to be a good form of care and rarely thought about other end-of-life care options. My own personal experience with hospice care opened my eyes to the

importance of the service and the impact it has on the family members who are left to mourn their loved one.

My grandfather passed in January of 2023, but his decline in health began many years before that. Around 2019 my family noticed changes in my grandfather's ability to move and speak. He developed a stutter and had difficulty moving his left arm. My grandmother was quick to find him rehabilitation services and continued their involvement in activities such as water aerobics. These activities seemed to help maintain his ability to engage in everyday life until Covid-19. The inability to engage in their previous exercise led to a faster decline in his health. As time went on, my grandmother continued caring for my grandfather and was able to get physical therapists to help manage his symptoms. However, this was not enough, and over the next three years his abilities further declined. His stutter turned into long response times and eventually an inability to speak at all. His difficulty moving his arm spread to his legs and he struggled to be able to stand up or walk on his own. My grandmother again responded with changes to their lifestyle to help accommodate him. They were able to purchase a recliner that helped him stand up, walkers, and a walk-in tub to help ease the bathing process. In the last few months of his life my grandmother became his full-time caregiver. She carefully prepared food that he would be able to eat, helped move him around, and ensured that he had everything he needed. My grandfather's inability to walk left my grandparents housebound for months. As my grandfather's symptoms continued to progress, my grandmother was unable to lift my grandfather and do the care work that was necessary. My parents began going to my grandparents' house twice a day to get my grandfather dressed and move him into the living room or bedroom when needed. During this time my grandfather was enrolled in hospice care. Hospice assisted my grandmother in procuring and setting up a hospital bed and provided other

medical devices to help them move through their day with more ease. During my grandfather's active dying period the hospice nurses reassured my grandmother that she had made the right choice and helped her understand that withholding food and water were better for his body. Hospice also provided medications to ensure that he was not experiencing intense pain. In the last few days my grandfather was able to sleep with his family at the house, and he peacefully passed away while everyone was talking to one another in a different room. After he passed, hospice assisted my grandmother in removing the medical devices that had been necessary for my grandfather. While the loss of my grandfather was painful, I was thankful for the help and relief that my parents and grandmother were able to receive through hospice care.

After this experience I felt deeply appreciative of hospice care and recognized that not everyone has access to, or desires hospice care. In processing my family's experience, I developed an interest in understanding how other people experience the end of life. I knew that hospice was a good service, however I did not fully understand the complexities it entailed as I had experienced the benefits from a distance. I started my research with the intention to understand the experience of hospice care through patients and to explore if hospice professionals and patient-family units felt like hospice care was doing enough to make the end of life as manageable as possible. I quickly learned that hospice care is anything but simple, and that it often did provide patient-family units with the deaths that they desired. The driving force of hospice care is the desire to care for all the needs of the hospice patient and their family members, however they simultaneously must survive as a business through the care provided. As I continued in my research my focus shifted to understanding how these two goals could function together and provide beneficiaries with better deaths.

When I began my research, I knew I wanted to be able to connect with the patient-family units who were going through this process. To get involved in the hospice world and patients within it, I began volunteering with Heritage Care Hospice in January 2024. I was assigned three patients in the Norman area and instructed to provide them companionship. The volunteer coordinator took me to meet the patients assigned to me and helped me to get oriented to the assisted living facilities that these patients were residing in. I began doing companionship visits on my own once every two weeks. I would visit with each patient anywhere from 30-45 minutes and then go about my day. As I kept visiting, I started bonding with the people I visited. Mrs. Story and I would sit with her tablemates and talk. Mr. Graham and I would watch movies or TV shows depending on how he felt that day. Mrs. Dean and I developed a particularly deep friendship, and during each visit we would read to one another after catching up on our week. As I continued to do visits, I noticed that the time I spent with these patients kept increasing. With the summer quickly approaching I decided to start visiting my remaining patients every week. The more frequently I visited these patients the more connected I became to other individuals in the assisted living facilities they resided in. I was able to have lunches with Mr. Graham which allowed me to hear about his tablemates' experiences with their living facility and the end of life. I developed a particularly close friendship with Mr. Collins, a man who lived at Mountain Top Assisted Living Facility with Mr. Graham. This relationship provided me with further opportunities to hear about end-of-life experiences. The ability to volunteer with Heritage Care Hospice allowed me to develop friendships with my interlocuters and provided me with occasional access to see care being given to the patients. Much of what I understand about hospice care was informed by my volunteer visits and the casual conversations about death and hospice that my interlocuters engaged in with me. I was often surprised by how willingly people

talked about death without me asking. Many times, I was afraid when our conversations would turn towards a dying friend or a facility resident because I was unsure about how everyone would feel, however I realized that being able to talk about the deaths of other people helped my interlocuters to process the loss of their friends and their own upcoming deaths. I slowly became more comfortable engaging in conversations about death and hospice care after a group of men started talking to me about other their own and other residents' health conditions while at lunch. Their ability to comment on death and bodily decay so freely opened a door for me to show my interest in what they were talking about. After participating in a death-centered conversation with the group of men I started to feel more confident in my ability to engage in difficult conversations about death and hospice care with those around me. I continued to carefully observe and gauge the ability of my interlocuters to talk about death to ensure that I would not upset or shock anyone that I talked with. Volunteering with Heritage Care Hospice brought me into a relationship with many of the people that I would later interview and provided me with the confidence I needed to engage in emotionally heavy conversations.

Methods

I began volunteering with Heritage Care Hospice in January of 2024 but did not begin conducting official research until July. To be eligible for an interview a person had to be receiving hospice care, be a family member of someone receiving hospice, or be a health care professional. To ensure that patients did not feel like they were being forced to participate, I ensured them that while I volunteered with Heritage Care Hospice, I had no control or influence over their care, and there would be no consequences for not wanting to do an interview with me. To further protect patients who were interested in doing an interview, I asked them follow up

questions about their comfort talking about death and hospice care to ensure that emotionally unstable participants would not be subjected to painful discussions.

To begin interviews I started with a small list of Heritage Care Hospice's patients that might fit the IRB eligibility criteria and be willing to conduct an interview with me[1]. Many of the individuals on the list were either ineligible or were uninterested in talking to me. I found less difficulty recruiting hospice professionals to be my participants which led to me to interviewing Heritage Care Hospice nurses before I talked to patients or their family members. The volunteer coordinator at Heritage Care Hospice would reach out to nurses that she thought might be interested in talking to me and explain the premise of my research. If a nurse was interested in talking to me, the volunteer coordinator would provide me with their contact information. With this information I was able to reach out to the interested nurses and set up in-person meetings where I would further explain my research and plan a future interview if the initial interest remained. These interviews were crucial to my understanding of hospice care and helped me to better understand what care was being provided and the heart behind the service before I interviewed patients and their families. When I transitioned into interviewing patient-family units I took a different approach to recruitment. Initially the volunteer coordinator at Heritage Care Hospice created a list of patients with their contact information that she believed would be willing to do interviews. I was able to get reach out and set up in-person interviews with one hospice patient and one family member through this list of possible participants, however I knew that this would not be enough to inform my understanding of hospice care. I made the difficult decision to ask my companionship patients and their family members if they would be willing to do interviews with me. I was able to get contact information for the family members of hospice

[1] Institutional Review Board Protocol approval number: 17215

patients through the volunteer coordinator or through the hospice patient themselves. I initially hesitated to ask my companionship patients to be my interlocuters as I did not want them to feel like I had only developed a relationship with them for my benefit. When I asked Mrs. Dean and other hospice family members to be a part of my research, they were more than willing to help me. Having the ability to speak to the family members of my companionship patients helped me to see their experiences with hospice in a new way. My companionship patients were the ones receiving physical care, but their family members were also receiving emotional care and were critical to understanding the full picture of how hospice care is experienced by the patient-family unit.

I was able to conduct 12 interviews with 10 different interlocuters with the interviews lasting anywhere from 45 mins to 2 hours. During these interviews I recorded my conversations with my interlocuters and occasionally took notes on interesting ideas or developing questions. While my interlocuters understood that we were doing an interview, I attempted to create a natural conversation by conducting semi-structured interviews where I followed up with questions to better understand their experiences and narratives. I interviewed three hospice nurses, one executive director of hospice, one Medicare insurance agent, two hospice patients, and three family members of hospice patients. All of my participants were white, urban, middle-class individuals who had received a high school education at the least. Most of my participants had received a college education and had experienced successful careers which they described to me during our interviews or my companionship visits. Two of my interlocuters, one hospice patient and one hospice family member, struggled with end-of-life finances, however both were able to find resources or rely on family members to ensure that their needs were met. The interlocuters who were receiving hospice care were all above 70 years old while the family

members of hospice patients ranged from 50 to 70 years old. Each of the patient-family units that I talked to live within 30 minutes of each other. This meant that family members were able to frequently visit their loved one and were nearby when emergencies occurred. This created an intimate knowledge of their hospice patient's experience of care, which they were able to describe to me. The hospice nurses that I interviewed had all worked in different care settings such as hospitals before becoming hospice nurses. Their experiences of care outside the context of hospice helped set up a contrast between the care that they provided in hospice compared to other settings. My understanding of hospice is informed by both the interviews I conducted and the conversations I was a part of during my volunteer times. After officially beginning my research, I continued volunteering with Heritage Care Hospice. My role as a companionship volunteer remained the same and I continued to read, watch TV, or eat with my patients as I had done before. Most weeks my companionship visits did not include any out of the ordinary events or conversations. When an unusual event or intriguing conversation occurred, I would record a voice memo after leaving and later type the experience up in my field notes. While most of my visits did not include out of the ordinary events, the daily routines and typical experiences of hospice patients helped me to better understand what it was like to receive hospice care over an extended period.

Pseudonyms and Interlocuters

Through this research I became friends with many individuals in the assisted living facilities that I visited. I developed a particularly close relationship with two of my interlocuters, the sister dyad Mrs. Dean and Mrs. Baker. I conducted two interviews with Mrs. Baker and visited Mrs. Dean weekly. I often found myself helping Mrs. Dean with little things such as setting up her phone or getting nurses at Creekside to assist her with bodily needs. As our

friendship developed, she began to call or text me during times when she struggled with mental stability. I found myself torn between my roles as a friend, a hospice volunteer, and a researcher because I knew intimate details about their lives that I would be unlikely to know if I had occupied only one of the three roles that I balanced. While I wanted to engage in a professional way with Mrs. Dean, I also wanted her to know that I was there for her when she needed me. This led to me prioritizing my friendship with Mrs. Dean over my role as a researcher and volunteer. While many times our relationship resembled two friends, I did my best to maintain a professionalism and healthy emotional distance between the two of us. Learning to navigate being a friend, volunteer, and researcher allowed me to engage with, form deeper relationships, and provide care for my interlocuters in a way that I would not have been able to do otherwise. I believe that this research helped my interlocuters to process their experience with hospice and identify parts of their care that could be improved by asking important questions. While I know that I did not perfectly navigate balancing my roles, I believe that I did help many of my interlocuters better navigate hospice care.

While writing about the individuals involved in my research, I wanted to protect their identities while also conveying the nature of our relationships. Everyone's name, assisted living facility, or hospice organization is referred to by a pseudonym. I have chosen to address my interlocuters with a formal title and a pseudonym last name to emphasize respect. While I have developed a deep friendship with many of the hospice patients and some of their family members, there remains a large age difference between us. When I visit with my companionship patients or talk to their friends at the facilities they reside in, I refer to them by their formal title and last name. There were a few interlocuters who insisted that I call them by their first names when we talked. When I began choosing pseudonyms and writing up my experiences, I decided

to continue addressing these individuals with their formal titles to continue to show them respect. To provide continuity in my writing I decided to refer to everyone with a formal title and pseudonym last name, even if that was not how I addressed them in person. I hope that my deep relationships with some of my interlocuters will come across in the stories they chose to share with me.

The following chapters and patient stories exemplify the complexity of hospice care. Hospice care goes beyond biomedical logics to provide care for the whole person and their family members, and in doing so it can be used as a model for how to improve medical care. I begin by exploring how the Medicare Hospice Benefit structures hospice organizations, and how this creates confusion and gaps in understanding for patient-family units. While the experience of navigating hospice care can be confusing it is a deeply appreciated service for beneficiaries. With an understanding of the structure of how hospice organizations function and its faults, I begin to unpack how hospice care is a form of medical care that extends beyond the constraints of biomedical care. The hospice nurses and the patient-family units I talked to highlight the importance of affective care and a holistic approach in hospice caregiving. Through a holistic approach and affective care, the patient-family unit experiences personhood care and whole person healing which is not available through biomedical care alone. Hospice care, while flawed, is a model for how standard biomedical health care services can evolve to provide better care for its beneficiaries.

Chapter 1 Gaps in Understanding Within Hospice Care

Pathways into Hospice

The end of life is a period fraught with loss, hardship, and confusion. End-of-life care options, such as hospice, are meant to make navigating this period more manageable for the patient-family unit. The people that comprise hospice organizations do a great amount of work to help patient-family units craft deaths that reflect personal desires, however, there often remains a high level of confusion that characterizes the experience of hospice care. While most hospice organizations have a genuine interest in serving people and ensuring their end-of-life experience aligns with their wishes, they also must make decisions to ensure that they remain in business. The experience of confusion begins with the pathways through which patients enter hospice. Each hospice patient has a unique pathway, which results in different experiences of confusion that often go misunderstood or unrecognized by hospice organization personnel. To begin exploring the confusion inherent in hospice care, it is important to start with the idealized hospice entrance as explained by a hospice professional and the actual lived experiences of two patient's pathways into hospice care.

Mrs. Tatum is the executive director for the Norman and Edmond locations of Heritage Care Hospice where she oversees the day-to-day operations of the two branches. She explained how patients enter hospice care from the hospice organization's perspective. To begin the pathway into hospice care, a patient's physician can reach out to a hospice organization and refer a patient. The physician must certify that the patient has a disease which has left them with only 6 months to live based on a normal disease progression. Family members, or hospice patients themselves, may also reach out to a hospice organization and request services. This can if the

hospice patient has decided to stop pursuing life prolonging measures and receive hospice care instead. If the patient is not referred by their personal physician, the hospice organization's physician will do a "Certification of Terminal Illness" to establish that the patient has a 6-month prognosis based on their best estimates. The hospice organization will then send out one of their nurses to do a hospice evaluation. After determining that the patient qualifies for hospice, the hospice organization will notify the patient's insurance provider (often Medicare) that the patient has elected hospice services. After informing the insurance company, hospice services can begin. Mrs. Tatum described the process of translating insurance from Medicare to Heritage Care Hospice as "a pretty seamless process." While the process of getting patients enrolled in hospice may be theoretically seamless, this is not the way that patients and families described their entrances and experiences with hospice care.

The real-life experiences of hospice patients and their families involve more complexity than the idealized hospice entrance. Mrs. Miller is one of two children and resides in Oklahoma near her mother, Mrs. Philips. In addition to suffering from Alzheimer's Mrs. Philips is blind and deaf. Mrs. Miller's brother has been largely uninvolved with their mother's caretaking needs as he lives outside of Oklahoma. Mrs. Miller first began taking care of her mother 14 years ago. Mrs. Philips resided about an hour and a half away from Mrs. Miller when she developed macular degeneration and glaucoma. Mrs. Miller and her husband began driving out to Mrs. Philips' house to take her to doctors' appointments and ensure that her needs were being met. After a short time, Mrs. Miller and her husband decided it would be best if they helped Mrs. Philips move into a rental property that the Millers owned a short distance from their own residence. Mrs. Philips adjusted well to the rental house; however, she continued to decline as she was 87 years old at the time. Mrs. Miller explained that as time went on, the financial cost of

caring for her mother became overwhelming. Mrs. Miller stated that they were paying about "$200-$300 a month" for needed medications. While trying to find a solution, the Millers discovered that hospice would pay for Mrs. Philips' medications and provide all her necessary care at home. The Millers received a recommendation for a hospice organization in the OKC area. After going through the certification process, they began receiving hospice services for Mrs. Philips. The Miller's experience with Mrs. Philips entering hospice care appears to be the "seamless process" that Mrs. Tatum described, however in talking further with Mrs. Miller it became evident that there were parts of hospice care that were not clear to her, such as disqualification policies and prohibited care actions.

Mrs. Baker's experience with her sister, Mrs. Dean, entering hospice reflects a more tumultuous pathway into hospice care. Mrs. Dean has struggled with bipolar disorder for most of her life, which has placed Mrs. Baker in the unique situation of knowing more about her sister's physical and mental health conditions than many other siblings. Mrs. Dean underwent a knee surgery that did not heal well, and after falling and re-injuring her knee, Mrs. Dean rehabilitated in a skilled nursing facility until she could move into her apartment at Creekside Assisted Living Facility. Mrs. Dean resided at Creekside for multiple years and experienced a slow decline in health. A year and a half ago, the staff at Creekside suggested that Mrs. Dean be enrolled in hospice care because they believed she was at the end of her life. Mrs. Baker did not believe that her sister was at the end of her life but agreed that Mrs. Dean would benefit from the services provided by hospice either way. Shortly after enrolling in hospice, Mrs. Dean experienced a sharp decline. Mrs. Dean's experience with hospice did not end with this decline, however the confusion that Mrs. Baker experienced with her sister's hospice care began around this time.

The confusion that both Mrs. Baker and Mrs. Miller experience stem from their loved one's entrance into hospice. Both women expressed the difficulty of navigating hospice care for others while dealing with their own personal health and life experiences. Mrs. Baker stated, "so many times when you're trying to take care of your loved one. You're also trying to take care of other things. Life is busy, you know, it just is. It is just more than one thing to have to take care of…" Mrs. Baker's statement highlights the expectation that caregivers be able to navigate their own life problems while also understanding and assisting their loved one through hospice care. Mrs. Miller's 13 years of caregiving has coincided with her own decline in health and a difficulty with navigating the government systems of Medicare, the medical insurance for individuals 65 and older, and Medicaid, the medical insurance for low-income individuals.

In addition to personal health and aging issues, the grief that often comes with entering hospice can cloud people's minds and create gaps in understanding that lead to confusion later in the process. Mrs. Tatum explained how she understands the confusion that patient-family units experience: "I feel like it's such an emotional [experience], like they're probably absorbing like 10% of what you're being told." The beginning of hospice care is often a time when the patient-family unit is still processing what it means to receive hospice services. Even those who have accepted that death is coming can find it difficult to focus their attention on the details of hospice care and their role in navigating the system. Mrs. Baker's experience with the pathways into hospice clearly demonstrates the difficulty of absorbing information. Mrs. Baker expressed that when Mrs. Dean was enrolled in hospice, she did not believe that her sister was at the end of her life. Mrs. Baker explained that in hindsight her disbelief "was denial" because she held out hope for her sister's life. The denial Mrs. Baker experienced limited her ability to absorb information at the beginning of the hospice journey. While Mrs. Miller did not experience a similar denial,

the root of her confusion stems from her sources of information. Mrs. Miller explained that she has difficulties navigating the internet to find the information she needs. Instead of searching for answers online, Mrs. Miller used her friends' experiences as her source of information. The lack of knowledge that many caretakers have regarding how to navigate the internet and access resources contributes to the confusion that they experience while navigating end-of-life systems. When searching for a hospice organization to enroll her mother in, Mrs. Miller decided to use the same organization a friend recommended. While receiving word of mouth-based information is critical to knowing how to navigate hospice, it also puts Mrs. Miller at a disadvantage because each patient-family unit's experience of hospice is unique. Receiving information from word-of-mouth personal experiences created gaps in the knowledge that Mrs. Miller had about navigating hospice.

Insurance companies are critical to the functioning of medical systems. Tom Baker, a law and health sciences professor explains that insurance companies actively construct the world that they are a part of by labeling people, institutions, and actions in terms of risk (Baker, 2002: 48). Insurance benefit policies such as the Medicare hospice benefit are actively constructing the world of hospice care to operate primarily as a business. The shaping of hospice into a business will be discussed further in connection with the establishment of the Medicare hospice benefit. Since hospice care has been transformed to function primarily as a business it has become more confusing for the patient-family unit to navigate. An important part of risk is finances. While hospice is not seen as a particularly risky institution, there is a risk that the hospice organization will not be a viable business if the right kind of patients are not enrolled in the organization. The increasing importance of making money means that hospice organizations have to ensure that they are providing high-level, quality care while also not spending an excessive amount of

money on the patient's care. Medicare, as a government insurance program constructs the world it is a part of by establishing a structure and opportunity for hospice organizations to be financially viable organizations.

The increased difficulty in navigation and general confusion when medical care begins to function like a business under government programs was demonstrated by anthropologist Louise Lamphere in her explanation of the consequences of Medicaid managed care in New Mexico. When Medicaid managed care was implemented, patients became responsible for figuring out how to access and navigate the bureaucracy of the governmental system to receive their health care. This expectation created considerable confusion and difficulties for both the patients and the care providers (Lamphere, 2005). While hospice organizations infrequently deal with Medicaid, the experiences in Lamphere's ethnography are still relevant as Medicaid and Medicare are both government medical insurance programs. While Medicare has enabled millions of people to receive hospice care, it also introduced confusion into the experience of hospice due to the emphasis of hospice organizations to maintain a viable business.

How Medicare and Hospice Function Together

Medicare

To understand how hospice care has begun to function as a business, it is necessary to understand the basics of Medicare. Mrs. King, a Medicare insurance agent explained to me how Medicare was structured and its interaction with hospice organizations. Mrs. King has been selling Medicare for multiple years in three states. This has given Mrs. King a deep understanding of the structure of Medicare and how it interacts with hospice care. Mrs. King detailed part A-D plans and Medicare supplement plans to explain how a Medicare beneficiary

moves from a Medicare plan to hospice care. Part A Medicare covers hospitalizations. Part B covers doctors' visits and requires a monthly premium of $185. Part D is for drugs and varies depending on the type of policy an individual is able and willing to purchase. Mrs. King described Medicare supplement plans as "the best of the best." These plans cover part A, and B plans with a needed part D plan to be added. Part C plans are often called "Medicare advantage plans" and include parts A, B, and D plans. As briefly described, to move from Medicare to hospice care, the hospice organization must certify that the patient has a 6-month prognosis and notify the patient's insurance that they will be enrolling in hospice care. Once the hospice organization notifies Medicare that the patient has enrolled in hospice the patient will leave their part C plan and move back to part A and part B plan where "hospice takes over at no cost." Mrs. King explained that "Medicare pays for hospice 100%" because "everything that's done under hospice is covered under original Medicare." Once again, the process to move from Medicare to hospice care is intended to be smooth, but when experienced by patient-family units there is always more complexity to the situation. These complexities will be addressed later, but for now it is critical to understand the ideal pathway from Medicare to hospice care to understand the gaps that patient-family units experience.

Understanding Medicare is critical to understanding end-of-life care because it is what dictates what kind of care is appropriate and desired. In Sharon Kaufman's ethnography *Ordinary Medicine,* she details the way that Medicare has becoming a "legitimizing tool" (Kaufman, 2015: 105). When clinical trials, new medical technology, or other advances in medicine are shown to improve or extend people's lives Medicare then becomes responsible for reimbursing that practice. Once physicians and medical institutions know that the practice will be reimbursed, and that there is a potential for benefit to the patient, the practice becomes standard

care (Kaufman, 2015). Kaufman explains this phenomenon through transplants and cardiac medical devices for older individuals in which high risk procedures are being performed on older individuals because once a therapy becomes reimbursable by insurance it becomes the standard of care (Kaufman, 2015: 7). Kaufman's work highlights the importance of Medicare in establishing standards of care in the end of life. While Kaufman's ethnography focused on life-prolonging medical care, her insights into the importance of Medicare apply to hospice care as well. Hospice care has become a standard of care because it is now reimbursable through the Medicare hospice benefit. The Medicare hospice benefit provides hospice organizations with structure, a source of income, and steady patient loads because it is now one of two standards of care for the end-of-life.

Medicare's Creates Structure for Hospice

Having a general understanding of how Medicare functions and how it transitions into hospice allows us to understand how Medicare creates the structures that hospice organizations follow. The structure that is created by Medicare contributes to hospice organizations being run as businesses where a main priority is reducing costs and ensuring that the business is financially viable.

Hospice began as a social movement that wanted to provide an alternative way for cancer patients to die. As hospice developed it became a Medicare benefit. Vincent Mor and Joan Teno, both health service researchers, track the entrance of hospice into the world of government regulated Medicare. In the U.S., hospice care started in 1974 as a social movement that "operated outside of the health care system" with the desire to provide a kind of care to dying individuals that they could not receive in standard health care systems (Mor and Teno, 2016: 698). By 1980 the Health Care Financing Administration (HCFA) began a study to determine the quality of

hospice care and how much it cost organizations to provide such care compared to hospital-based care (Mor and Teno, 2016). Wallace, a professor of nursing, provides more insight into this study. From 1967 to 1974 the cost of health expenditures for Medicare and Medicaid tripled, led mostly by the frequency with which hospital physicians provided costly life-prolonging interventions to individuals who would not survive. This massive increase led the HCFA to consider adding hospice as a benefit under Medicare to reduce costs (Wallace, 2015). Hospitals are structured to provide life-prolonging care to individuals who have the potential to live longer. Even when patient's potential to live longer was slim, these high risk, expensive, and often painful procedures were being continued. Hospice care seemed to be an alternative. Hospice provided high-level care but did not cost nearly as much as standard life-prolonging care. Patients had better experiences, and less money was spent on the care of the patient. The potential to save money and provide quality care attracted Medicare to look closer at hospice care. As Wallace, Mor, and Teno explain, there was an urgent need to find a solution to the rapidly growing costs of health care services. The study conducted by the HCFA concluded that making hospice care a benefit under Medicare would help cut down on health care costs due to the decreased number of hospital visits that hospice patients experienced. By 1982 hospice had been made a Medicare benefit, but the legislation was written with "a number of provisions that sought to limit costs" (Mor and Teno, 2016: 701). One such provision was that patients were only allowed to be enrolled in hospice 210 days (or about 7 months). The 210 days were broken down into two 90-day periods and one 30-day period, which were meant to ensure that the costs of hospice care did not exceed that of hospital based standard end-of-life care (Mor and Teno, 2016). This provision meant that people who outlived their 6-month prognosis were discharged from hospice and had to return to their Medicare plans and receive standard hospital-based end-of-life care which was

both high cost and largely ineffective at providing the care needed during the end of life. After lobbying by hospice and advocacy groups, legislation in 1986 opened the Medicare hospice benefit to beneficiaries in nursing homes, and amended the eligibility procedures to include two 90-day periods and an unlimited number of 60-day periods if a physician could certify that the patient still had a 6-month prognosis (Mor and Teno, 2016: 703). Hospice became a standard of care through the Medicare hospice benefit and spread rapidly cross the nation.

The daily functioning of hospice organizations continues to be structured by Medicare regulations. While talking to Mrs. Tatum, the executive manager at Heritage Care Hospice, about the rules that they must follow, she explained that they "operate totally off of Medicare guideline[s]. That's the strictest, so that's what we operate off of." Mrs. Tatum further explained that while most patients have Medicare, there are some patients who come to hospice care with private insurance. To ensure that Heritage Care Hospice does not have to pay back private insurers due to inappropriate hospice service usage, the company follows the strict Medicare rules. By operating according to the Medicare guidelines Heritage Care Hospice ensures that the requirements of private insurers are met. When I asked about some of the rules that Medicare created Mrs. Tatum explained the eligibility criteria and the necessary care practices that they follow. As explained earlier, the company physician must visit the patient and certify that they are eligible for hospice care. After the first set of 90 days, Heritage Care Hospice sends a registered nurse (another requirement by Medicare) to do a "recertification" in which the patient is assessed. Recertification was described as a "kind of comparing, like where you [the patient] were last certification period, and this is how you [the patient] declined." Mrs. Tatum emphasized the importance of being able to document and demonstrate a decline in patients. If no decline can be found, then the patient becomes ineligible for hospice services according to

Medicare. Medicare not only creates regulations for eligibility, but it also provides the expected structure for care. Sarah Wilson, a professor of nursing at Marquette, explains the other requirements of hospice organizations under the Medicare hospice benefit. The hospice organization must provide "nursing, medical, social work, and counseling…employ a medical director…. Be available on a 24-hour basis… have cost savings realized through volunteers… [and have] bereavement counseling" (Wilson, 1993: 358). The Medicare hospice benefit has created a strict structure for hospice organizations to follow regarding what services are available, when services are expected to be given, and what kinds of patients hospice organizations can serve. Wilson explains that the Medicare hospice benefit "legitimized the hospice concept in the United States" while also creating "a source of revenue for hospice programs" (Wallace, 1993: 357). As both Kaufman and Wallace highlight, The Medicare hospice benefit confirmed that hospice care was quality care; furthermore, it created a structure for organizations to ensure quality care was experienced across the country. Most importantly, however the Medicare hospice benefit provided a way for hospice organizations to be financially viable businesses. In doing this, hospice moved from a volunteer led, health care social movement, to a medical service structured as a business.

Medicare Funds Hospice Organizations

While hospice organizations can be non-profit, most hospice organizations in the U.S. are for-profit organizations because of the Medicare hospice benefit. Heritage Care Hospice is a for-profit business, therefore the analysis of how Medicare impacts hospice organizations will focus on for-profit hospices. In our conversation Mrs. Tatum began to illuminate how a hospice organization can be a viable business through Medicare. Medicare pays Heritage Care Hospice (and every other Medicare based hospice) a per diem. The per diem rate for routine home care

patients was updated for the 2025 fiscal year by the state of Oklahoma to be $217 for the first 60 days and $171 for any days after (Oklahoma Health Care Authority, 2024). When I asked what happens if the care provided exceeds the allotted per diem Mrs. Tatum explained that "if [the care is] something that is directly related to their hospice diagnoses, we're paying for that, and if it's not, then the patient or patient family is. That will be billed to their insurance." Mrs. Tatum's explanation did not fully clarify how hospice organizations make money, but it explained the importance of making sure that the care provided was only for their hospice diagnosis.

Zuckerman et al. explain that hospice organizations "receive a per diem payment at one of four levels (routine home care, continuous home care, inpatient respite care, or general inpatient care)" with 95% of the care being routine home care (Zuckerman et al. 2015: 569). The per diem for each of these levels varies due to the different levels of care being provided, however no matter what level of care the patient receives within a level, the per diem remains the same. Wallace explains the reimbursement process, noting that if the services that are provided by the hospice organization cost less than the per diem given by Medicare, then the hospice gets to keep the remaining funds from Medicare as a profit (Wallace, 2015). Hospice organizations can make money by providing care that is less costly than what Medicare expects them to spend. Aldridge et al. highlight the importance of the per diem to running a viable business, explaining that the "Medicare hospice benefit accounts for 84 percent of annual hospice revenue" (Aldridge et al. 2012: 2691). The ability to run a viable business through Medicare funds has begun to be addressed by legislation regarding the per diem funding for hospice. A report to the congress on hospice care in 2013 suggested changing the flat per diem rate to a U-shaped per diem rate where the per diem would be higher at the beginning and end of a patient's hospice enrollment. At the beginning of care the organization would receive a higher per diem since enrolling and

establishing a patient in hospice care is more expensive. After stabilizing the patient, the cost of care typically decreases, so the per diem allotted from Medicare would decrease. The per diem would then retroactively rise back up during the last few days of life as care often intensifies during this time. Hospice labor costs were found to be the highest at the beginning and end of hospice enrollment. When patients were in hospice care for longer than the average stay, the number of days where the patient was stabilized increased. This stabilization resulted in lower labor and medical costs. Hospice organizations were able to make a greater profit margin when patients remined in a stabilized, low-cost condition for longer periods of time because the per diem rate never decreased as the costs of care decreased. The U-shaped per diem rate would change the per diem to reflect the lower labor costs associated with the middle days of hospice care where the patient was stabilized and required less care (Medicare, 2013). The U-shaped per diem is not in effect today, however it demonstrates the importance of Medicare to hospice organization's ability to make money and run viable businesses.

To cut down their own expenditures Medicare was seeking to alter the per diem of hospice care. While Medicare did not implement a U-shaped per diem, they did decrease the per diem rate after 60 days of the patient being enrolled in hospice. Medicare not only creates the structure for hospice organizations, but it also creates the ability to be a finically viable business if the organization's patients only require low-cost treatment. Hospice organizations strive to serve people's needs at the end of life; however, they must also balance that desire with the necessity of running a financially viable business. Hospice became a benefit under Medicare due to the need for Medicare end-of-life costs to be reduced. The desire to reduce costs has extended from Medicare into hospice organizations. Today, the business model structure contributes to the confusion that patient-family units experience throughout their care.

Information and Confusion

Medicare and Hospice Confusion

Hospice care reaches millions of Americans because of the Medicare hospice benefit; however, the entanglement of hospice and Medicare insurance is not always understood by the patient-family unit, which creates gaps of understanding and confusion for beneficiaries. The connection between hospice organizations and the public-run system of Medicare begins to explain why there is confusion in the system. While public systems are intended to provide for people's needs, they often are not efficient or navigable which creates confusion for those moving through the system. Mrs. Miller, the daughter who has cared for her mother for 13 years, spoke about the confusion that is created through government systems. After caring for her mother for an extensive time, the Millers were able to help Mrs. Philips go through the process of qualifying for Medicaid, which is the U.S. federal health insurance program for individuals with low incomes. Mrs. Miller discussed the difficulty of keeping track of her mother's Medicaid status and going through the process of qualifying every year. Mrs. Miller described "a horrible situation" that one of her friends encountered where the friend needed to enter an assisted living facility (which often cost $10,000 or more a month) to receive extra caretaking help, however he found himself unable to receive the care he needed because he had too much money to qualify for Medicaid, but not enough money to reside in an assisted living facility. In describing this situation and her own experiences with government systems, Mrs. Miller stated "There's a bad breakup. I mean there's a bad disconnect there. I mean these people that sit behind the desk, are the ones that I have a problem with. The workers out here don't like it either…that is the biggest problem." Mrs. Miller expressed her frustration with the creators of systems such as Medicaid

and Medicare. She believes there is a disconnect between those that design systems and those that must navigate the system. This disconnect breeds confusion that the average user is expected to navigate by themselves. While Mrs. Miller was discussing Medicaid, her experience and frustrations can be applied to Medicare as well. In my conversation with Mrs. King, the Medicare insurance agent, she discussed all the hoops that beneficiaries are expected to be able to jump through. “When you’re dealing with older people and they’re trying to jump through, even just the simple hoop of trying to sign up online for Medicare, they’re already scared out of their mind. I can’t tell you how many women I talked to, they’re like I just don’t wanna do it wrong.” Before beginning the process of entering hospice, Medicare beneficiaries are struggling to understand and navigate the Medicare system correctly. Part of the confusion that individuals experience with hospice under the Medicare hospice benefit is that there is no one they can consult before they enter hospice. After contacting a hospice organization, the patient-family unit will have a social worker who can provide information, but before that, Medicare beneficiaries are expected to navigate the system and enter hospice on their own. This means that often, patients’ experience with hospice care starts with confusion. When I asked Mrs. King if there was a way to clearly lay out the connections between Medicare, hospice care, and other important aspects of end-of-life care such as Medicaid, living facilities, and other assistance programs she explained that “there are a lot of missing links” and that “no patient or outside person could connect it to make it easier.” Even though there is no one can connect all the organizations and necessary end of life resources, hospice patients and their families are still expected to make connections between different resources to navigate the entire end-of-life experience.

Tom Baker, a professor of law and health sciences, gives insight into why individuals experience confusion in navigating the systems of insurance. There is a false belief that once an individual obtains insurance their responsibility has been lightened and redistributed towards the insurer, however insurance only assumes some of the responsibility of individuals (Baker, 2002). With this fallacy in mind, we can understand how patients and families may expect insurance programs, like Medicare, to help them navigate the system and lighten their responsibility, however this is not what happens. Wilson illustrates this clearly when she discusses the eligibility expectations of Medicare. To qualify for hospice under the Medicare hospice benefit the hospice patient must have a primary caregiver who is able to live with the patient and provide care when the hospice organization is not there. Hospice is available 24/7, but the care team is not available at a moment's notice like they are in hospitals. This means that the patient must have family members or other individuals, such as assisted living facility staff, who are able to be with the patient 24/7 and provide for their basic living needs. Wilson explains that the Medicare hospice benefit "emphasizes home care and has shifted the burden of care onto families" (Wilson, 1993: 356). Not only are families responsible for providing daily physical care, but they are also responsible for navigating systems that can never clearly be connected and understood because of their intricacies. Through the Medicare requirement of having a family caregiver, there is more responsibility placed on the patient-family unit than family members often expect. The Medicare hospice benefit is a breeding ground for confusion because of the expectation that patients and their families know how to navigate the systems.

As hospice has moved from a social movement to a Medicare benefit, the focus of hospice care has expanded to include financial viability. While hospice and business are not completely incompatible, the necessity of maintaining a financially viable business can alter how

patients experience care. The pathways into, and later the experience of hospice care, have become more complicated and confusing for beneficiaries. There seems to be no single, clear resource for people to access information that would help them prevent or clear up confusion. In the tangle of government insurance and hospice, people learn to navigate the system through word of mouth and friendships.

Word of Mouth

Mrs. Miller's experience as a caregiver has been significantly longer than the average caregiving period, which has allowed her to slowly move through the end-of-life caregiving process. Mrs. Miller's slow-moving experience has provided her insights into navigating the confusion of hospice and Medicare. When I returned to Mrs. Miller's house to conduct a second interview with her, she was excited to share her experience of navigating hospice. Mrs. Miller continually emphasized the importance of having friends who were walking through the same stage of life so that she could learn and share information. I asked Mrs. Miller if the length of time she has spent as a caregiver impacted her ability to handle the financial difficulties that accompany hospice, to which she responded " If you're going into this and you don't have any friends to kind of guide you with some ideas you're just gonna have to guess, it's all gonna be guesswork because, no, it's not out there unless you just hear it from somebody that knows, has been through it before. There were so many things I didn't know, and everything I found out from was from somebody…everything." Mrs. Miller exemplified why she believes that having friends to talk to is so important in her stories of learning the do's and don'ts of hospice care. Before her mother entered hospice care, Mrs. Miller was paying for all her living and health care expenses out of pocket. After paying "close to a $100,000" to take care of her mother, Mrs. Miller learned that her mother could qualify for Medicaid after one of her friends went through a

similar experience. After qualifying for Medicaid, Mrs. Miller was informed by another friend, who owns a nursing home, that she should not enroll her mother in a Medicare advantage plan because it could disqualify Mrs. Philips from receiving Medicaid. Mrs. Miller described word of mouth as "priceless" during the end-of-life period. She had multiple friends give her phone numbers to services and programs that they had used so that she did not have to navigate the internet to find answers or contacts to help her. Mrs. Miller discussed the way that she has started sharing any information she has with people going through similar situations so that they can have an easier time navigating the system.

In Javier Auyero's ethnography he explores the experiences of poor people's waiting in welfare offices in Buenos Aires. The people waiting to receive welfare are forced to navigate a system that is inconsistent with its payment schedules but constantly requiring beneficiaries to be present to receive their welfare payments. Through this process the welfare system controls and takes advantage of those who need assistance by forcing them to wait. Auyero explains that it is in the waiting that people share their experiences and learn about benefits. Waiting becomes relational (Auyero, 2011). While hospice care does not place people in physical waiting rooms, it does create a metaphorical space of waiting for a loved one to pass. While in this waiting period, patients and families can connect with their friends and extended family and share their experiences and what they have learned about navigating hospice care. The hospice waiting period can be thought of as a relational space. Mrs. Miller has experienced a particularly long waiting period regarding her mother's death, which has allowed her to engage in relationships with people and learn about services and benefits that make the end of life more navigable. While relationships and word of mouth information is crucial during this time it is not enough to prevent confusion in hospice. Each hospice experience is unique and can only provide elements

of how to navigate hospice and the end of life in general. Well-intended false information can also cause further confusion and strife in navigating the system. For those who do not have access to word-of-mouth experiences with hospice, navigating the system remains, as Mrs. Miller said, "guesswork."

Guesswork-ing the system

While Mrs. Miller has had an extended time to learn how to navigate the system and eliminate the guess work, Mrs. Baker has had considerably less time. Mrs. Baker's sister, Mrs. Dean has been in hospice for a year and a half, which is a much longer hospice enrollment than most patients, however Mrs. Baker has been engaging in "guesswork" during this time. Mrs. Baker's situation is also unusual in that she is heavily involved in her sister's care, but she does not have power of attorney. Mrs. Dean's eldest son holds the power of attorney and is active in Mrs. Dean's care, however he lives in California which restricts his ability to be present for his mother's needs. Mrs. Baker lives a short driving distance from Creekside Assisted Living Facility and is frequently the family member that is called when something happens with Mrs. Dean. Multiple times Mrs. Baker has found herself in situations where she is expected to sign for her sister without knowing if she has the legal right to. Mrs. Baker explained that she is "never in one of the meetings…nobody's trained me…they think I know, but I don't, and I don't know what to ask." Mrs. Baker expressed confusion regarding her sister's care. She described the care as "a big bowl and I don't know which pieces are what." Mrs. Baker's precarious position as the closest relative, but without the power of attorney leaves her to navigate hospice care through guesswork. Mrs. Baker does her best to show up for her sister and care for her, but her lack of information prevented her from even knowing what kinds of questions to ask to ensure that Mrs. Dean was properly taken care of. For Mrs. Baker, hospice is experienced as a waiting period, but

the relational aspect of waiting is largely missing which contributes to her confusion. In talking about her experiences with structures in place for the end-of-life, Mrs. Baker explained that even when there is "kindness" in an organization, there is also "legal efficiency." Mrs. Baker believes that even when people desire to help others navigate the system, they must do so in a way that complies with laws and prioritizes efficiency which creates confusion.

While hospice care organizations strive to provide high level care, the necessity of running a financially viable business leaves those in the system without the proper resources to navigate hospice. This creates gaps of confusion for people like Mrs. Baker and Mrs. Miller. Mrs. Baker's precarious position as a semi-primary caregiver excludes her from typical modes of receiving information but still requires her to be able to navigate the Medicare hospice benefit. Gaps in information occur not only for precarious caregivers, but also for the most involved caregivers like Mrs. Miller.

Financial Difficulties

Unexpected payments

One of the most common gaps of information that patient-family units experience is unexpected payments for life-prolonging forms of care. To be eligible for hospice under the Medicare hospice benefit, patients must forgo any life-prolonging treatment. While some forms of life-prolonging care are obvious, such as chemotherapy or trial drugs, other forms of life-prolonging care go un-noticed by the patient-family unit and result in expensive, unexpected charges. In her explanation of how Heritage Care Hospice functions, Mrs. Tatum provided insight to how a patient can incur unexpected charges. If the care that a patient receives exceeds the per diem allotted and is "directly related to their [the patient's] hospice diagnosis" the

hospice company will pay for the care. However, if the cost of care exceeds the per diem and is not related to the terminal diagnosis "the patient or patient family…[is] billed to their insurance." Mrs. Tatum's statement starts to illuminate the root of confusion related to unexpected payments in hospice.

Hospice is a benefit under Medicare that is intended to be completely paid for, however what is often unknown is that treatments unrelated to the terminal disease are the responsibility of the patient and their family. When I asked Mrs. Tatum about the confusion that many patient-family units experience regarding what is paid for, she explained to me the way that information is made available to patients. "There's an option for them to, like on the paperwork that they sign, whenever they get admitted, to be notified of stuff that's not covered by hospice… not very many people take advantage of that really, because there are medications that, like, we won't cover. So, if there's, you know, a certain medication that they're wanting to stay on, like, we're very transparent… [the patient-family unit will] be responsible for this one. This is what hospice will cover." When asked about how the "transparency" was conveyed to patients she explained that patients can receive a physical document with what is covered by hospice, but only "once they actually request that list, that itemized list of this is what hospice does not cover, then yeah, they get something in writing, and we have like five days to provide that." To gain access to information about what medications are paid for by hospice, the patient-family unit must request the information. To even begin this process the patient-family unit must be knowledgeable enough to know to ask for the itemized list, or during the admittance process they must read through the documents thoroughly enough to catch that they can request this list. While there is written documentation of the right to an itemized list, consent and enrollment forms are often not read thoroughly or are read under a time constraint which limits people's ability to fully

comprehend and remember what they are reading. In addition to this, Marie-Andree Jacob, a professor of law, explains that consent forms are accompanied with the belief that quickly moving through paperwork is a necessity, and consent forms are something to just get through (Jacob, 2007). While Jacob was writing about consent forms in hospitals, her findings apply to the enrollment and consent processes for hospice. Patient-family units understand that to begin receiving care they must first move through the process of signing papers. There is often an urgent need for the hospice care to begin as soon as possible. This creates a situation where the enrollment process is sped up, and rules and regulations are not thoroughly understood. The need to quickly enroll people in hospice results in confusion about health care coverage and often ends with patient-family units owing a considerable about of money for life-prolonging care or medications.

Mrs. Baker and Mrs. Dean's experience highlights the confusion between which medications are covered by hospice care, and which are not. When I asked Mrs. Baker about any experiences with medication or insurance coverage problems, she explained to me how Mrs. Dean was currently struggling with navigating payments to Omnicare, a CVS pharmacy company that provides medications to long-term care and senior living facilities. Mrs. Baker learned about the charge after going to visit Mrs. Dean where she found her crying over the bill. Mrs. Dean had been given a bill every month but had never made a payment which accumulated to a total of $3,400 that needed to be paid. Initially Mrs. Baker did not know why Mrs. Dean would have charges from Omnicare, but during our conversations she began to realize that Mrs. Dean's medications for depression and bipolar disorder would not be covered by hospice because they were not a part of her terminal diagnosis. Mrs. Baker remained unsure of how Mrs. Dean had incurred a bill for Omnicare because to her knowledge, Mrs. Dean had never signed up for

the program. When I talked to Mrs. Baker, she told me that Mrs. Dean had set up a payment plan for Omnicare, but she was unsure if money was actively being taken out of Mrs. Dean's account to pay the $3,400. Mrs. Dean and Mrs. Baker's situation is complicated by the assisted living facility where Mrs. Dean resides. It is likely that Mrs. Dean accumulated the charges through Creekside and the medications that they provide her. While this situation is particular in that it involves a living facility, it speaks to the confusion that patient-family units experience regarding medications and permitted acts of care. Mrs. Baker was under the assumption that hospice had been paying for all of Mrs. Dean's medications and care. It was not until the bill came in that she discovered that hospice would not pay for everything Mrs. Dean needed. The necessity to request itemized lists of allowed medications placed Mrs. Baker and Mrs. Dean in a situation where they now must navigate paying an unexpected bill.

Mrs. Baker and Mrs. Dean are not the only ones who have experienced an unexpected charge for life-prolonging care. Unexpected charges can be accumulated in addition to charges for assisted living facility care. During my second conversation with Mrs. Miller, she emphasized things to "watch out for" that could make navigating hospice more difficult. She explained their experience with an unexpected payment. Mrs. Philips, Mrs. Millers mother, had issues with her knees that cause discomfort. Before entering hospice care, Mrs. Miller would take her mother to receive knee injections to help relieve the pain in Mrs. Philips' knees. Medicare paid for the $2,000 injections until Mrs. Philips was enrolled in hospice. Mrs. Miller continued to take her mother to get these injections while receiving hospice care, however this time they were required to pay the $2,000 charge on their own. Mrs. Miller was able to explain the situation to the company that provided the injections and was not charged for the care, however she was informed that she would no longer be able to take her mother to get injections

because they were a form of life-prolonging care unrelated to her hospice diagnosis. When asked if she knew what acts of care hospice permitted, Mrs. Miller made it clear that she did not understand what was prohibited. She explained that she was probably given an informational booklet, but that she had not read through it and had placed it the designated drawer for her mother and moved on. Mrs. Miller's experience once again highlights the confusion that is created by requiring patient-family units to read through booklets, enrollment, or consent forms to gain critical information. The enrollment process for hospice is a period when people are trying to move efficiently to obtain care for themselves or their loved ones and they do not have the time to read paperwork to know how to navigate the system and avoid unexpected payments. Furthermore, as Mrs. Tatum explained, even when information is given to patient-family units they absorb "10%" of what they are being told. Even if patients were verbally told what medications or care acts are covered under hospice, they would be likely to forget it. The Medicare hospice benefit requirement that patients request itemized lists of what is covered makes the system more difficult to navigate during an already fraught time. This results in the patient-family unit experiencing high levels of confusion and often getting saddled with expensive unexpected payments. Mr. Miller's story exemplifies a gap in understand between hospice organizations and patient-family units. Hospice organization staff members have a clear understanding of what kinds of care acts are acceptable and refundable because the Medicare Hospice Benefit has clearly laid this out for them. Hospice patient-family units lack this same kind of clarity due to the stress that accompanies the end-of-life. Patient-family units are often more focused on their loved one's needs and either do not remember, or do not read the guidelines that hospice organizations operate through which results in unexpected payments for patient-family units.

Navigating Private Insurance with Hospice

Most hospice patients are enrolled in, and pay for, their hospice care through their Medicare insurance plans. However, individuals sometimes have additional private insurance plans to supplement their Medicare coverage, or they decide to continue paying their Medicare supplement plans to retain the same insurance coverage they had before enrolling in hospice. Patient-family units must navigate having the right kind of insurance to ensure that any non-hospice care is paid for, while also not wasting money for unneeded insurance plans. Mr. King described retaining a Medicare supplement plan while on hospice as a "catch-22." Patients and their families are scared to "lose their health insurance" in case they might need it for an unexpected reason; however, they continue to pay for this insurance when its often unnecessary as death draws near. Mrs. Tatum further elaborated on this issue by explaining that while enrolled in hospice, patients are still able to go to doctors such as "dermatologists" but that they would be billed through their insurance. As Mrs. Miller's experience illustrates, the difference between hospice-covered care and non-covered care is not always clear. Hospice patients may continue to go to regularly scheduled doctors' visits, such as dentist, optometrists, or dermatologists, however they become responsible for the charges without being fully aware of their responsibility. Donald Taylor, a health policy scholar, explains that retaining additional insurance, such as a private insurer, helps reduce the out-of-pocket costs for the patient-family unit (Taylor, 2009). If patients keep their additional insurance, they are guaranteed to have access to services like dentists. However, this is a difficult line to walk as there is no guarantee that the hospice patient will need to continue visiting physicians or medical specialists outside of hospice care. Patient-family units must navigate the decision to release their additional insurance benefits

without the guarantee that their loved one will have all their needs met outside of the terminal diagnosis.

While some patient-family units are navigating the decision to let go of the added safety net of additional insurance, other individuals unknowingly pay out thousands of dollars for insurance that is not being utilized. When I asked Mrs. Miller to describe instances of difficulty that she has faced regarding health insurance, she explained to me that she had been paying for an unnecessary supplemental insurance without realizing it. Mrs. Miller paid Blue Cross Blue Shield "like four hundred and almost five hundred dollars a month" because she had created a habit of paying them. Mrs. Miller described "a light bulb finally [going] on" when she realized that she was unnecessarily paying this bill. She started thinking about how her mother receives both Medicare and Medicaid and decided that the supplemental insurance was unnecessary. When she contacted Blue Cross Blue Shield, they suggested that she keep the insurance just in case Mrs. Philips needed it. After going through files Mrs. Miller realized that she had been paying for unnecessary supplemental insurance for over a year. She attempted to have this money refunded but was unable to do so. Mrs. Miller described realizing that she was paying for supplemental insurance as a light bulb that she just happened to turn on. If she had not experienced this realization, she would have continued to spend thousands of dollars a year for insurance that was not being used.

Ericson et al. explore the way that private insurance partners with the state to create tools for people to become more responsible for their own well-being and that of others. Private insurance governs at a distance through surveillance. In doing this people have to be responsible for themselves and others to ensure the best outcome (Ericson, 2003). Mrs. Miller's experience is an example of private insurance forcing people to be more responsible for their own well-being.

Mrs. Miller had to become aware that she was paying for supplemental insurance unnecessarily. There was not a place for her to find information about navigating insurance after enrolling in hospice care. Her experience re-iterates the importance of having relationships where people can share their experiences and give advice about the end of life. By engaging in word-of-mouth sharing of information about benefits, programs, and catch-22's, Mrs. Miller is becoming responsible for her own well-being and others' well-being, as Ericson et al. suggest will happen.

While Ericson et al. claim that state insurance systems are not using the same tools to make people more responsible, the examples of hospice care highlight the way that individuals are forced to be responsible for their own and others' well-being. Hospice care under the Medicare hospice benefit requires the patient-family unit to navigate the system without a road map to guide them. Beneficiaries move through hospice by guesswork and word-of-mouth personal experiences or advice. Without clearly explained and accessible information, patient-family units find themselves in complicated financial situations that cause their experience of the end of life to be more difficult than it has to be.

Hospice Eligibility and Disqualification

Lack of Clarity in Qualification

Navigating the pathway into hospice and dealing with complicated insurance systems are parts of hospice care that nearly all patient-family units will have to deal with. Most individuals will only spend about 18 days in hospice care (Wallace, 2015). For patient-family units that experience extended enrollments in hospice they must learn to navigate the lack of clarity and confusion inherent in the qualification procedures for hospice care. The difficulty of navigating the unclear hospice policies is compounded by the stress, intense changes, and difficult emotions

that are already experienced due to the nature of the end-of-life. There seems to be little bandwidth to navigate the complexities of hospice while balancing the intensity of the end of life as demonstrated by the experiences of the hospice family members that I talked to. One of the difficult experiences that my interlocuters described was the hospice qualification policies.

The Medicare hospice benefit requires hospice organizations to re-certify that patients qualify for hospice in two 90-day periods followed by an unlimited number of 60-day periods. Mrs. Tatum explained recertification this way:

> For a recertification visit, that has to be a registered nurse as well. They do the assessment…it's kind of comparing, like this is where you were last certification period. And now this is how you declined. It's really all about showing that the patient is, you know, progressing in their disease process. So, what are some of the things that they look for to show that they're progressing in the disease process? So, like if a patient can't stand up anymore because they're too weak to weigh, we do something called the LMAC. And it's the left mean upper arm circumference. We'll measure that, and then we'll just compare. So that kind of shows muscle wasting and stuff like that. Where if your upper arm is 20 centimeters and now it's 18 that shows a decline. Cognitive function, if they are requiring more assistance with ADLs [activity of daily living], like maybe before they could need, like, a standby assist in the shower, but now you're totally dependent on somebody for your bathing needs and stuff like that. Food intake. Respiratory distress, pain, stuff like that.

When I asked how someone experiencing normal aging processes would be labeled eligible for hospice Mrs. Tatum explained that to ensure eligibility for these patients, physicians can label patients with diagnoses such as “protein calorie malnutrition” to ensure that the patient received the needed care. The lack of clarity in the 6-month prognosis means that physicians can establish eligibility or discharge patients from hospice based on their own subjective understandings of the patient’s disease progression. Mrs. Tatum described this lack of clarity as the ability of physicians to use their own judgment regarding patients’ conditions. Aldridge et al. explains that the enrollment decisions of hospice providers can contribute to underuse of hospice services by patient-family units that truly need the help (Aldridge et al. 2012). When eligibility requirements

are unclear, the physician is burdened with the ability to extend or retract needed services from dying individuals. This lack of clarity creates confusion for those moving through hospice care.

While some of the recertification activities give objective numbers that reflect a decline, often physicians decide the eligibility of a patient based on their subjective opinions about the patient's state of wellbeing. This was expressed to me by Mrs. Miller who described showing a decline as a "fine line" that her mother walked due to her relative good health. Mrs. Miller's mother, Mrs. Philips, has been in hospice for the last five years with the diagnosis of congestive heart failure. She explained that hospice decided to diagnose her mother with congestive heart failure due to swelling around various parts of her body. Mrs. Miller explained that she didn't want to "cheat" for qualification, but that she "just let them do what they needed to" to keep her mother eligible for hospice care. The swelling that her mother always had allowed the hospice team to "always come up with something" during recertification. The lack of clarity of recertification left Mrs. Miller frequently wondering if her mother would continue to qualify for hospice. This issue was not a point of stress for Mrs. Miller, but rather another aspect of hospice care that created confusion and difficulty navigating the system.

Mrs. Baker expressed a similar confusion over how Mrs. Dean continued to qualify for hospice care a year after her initial enrollment. After Mrs. Dean enrolled in hospice, she experienced a sharp decline and appeared to be actively dying, however within a week she rebounded and was able to slowly regain the ability to move around and interact with people. Since then, Mrs. Dean has experienced multiple declines followed by rebounds in health. Mrs. Baker explained that with each rebound Mrs. Dean never reached the level of health that she previously had. This situation makes showing a constant decline for hospice qualification complicated. Mrs. Baker explained to me that multiple times in the past year a member of the

staff at Creekside Assisted Living Facility has informed her that Mrs. Dean was about to be taken off hospice. Each time Mrs. Dean was not taken off hospice, but Mrs. Baker and Mrs. Dean prepared for the situation as if they would no longer receive the services from hospice that they were getting. Mrs. Baker is still unsure if Heritage Care Hospice communicated a possible discharge to the staff member, or if the staff member made the statements about discharge based on her own perceptions. Either way, Mrs. Baker and Mrs. Dean have been left with more confusion about Mrs. Dean's eligibility for hospice care. The lack of clarity of hospice qualifications create confusion for patient-family units like Mrs. Baker and Mrs. Dean, in which they must prepare for the worst-case scenario which has yet to happen. While Mrs. Baker and Mrs. Dean have not had to face disqualification and a release from hospice care, other hospice patients have had to navigate this experience.

Disqualification

Live discharges occur when hospice patients do not show a decline in their condition, or if they engage in activities that are prohibited by the hospice organization or Medicare guidelines. Mrs. Tatum described a few instances that would lead someone to a live discharge. One of the most frequent ways to initiate a live discharge is an emergency room visit. Patients are allowed to visit the emergency room on a case-by-case basis. The hospice organization can discharge a patient if there has been an emergency that requires hospitalization to immediately stabilize the patient's condition. This could happen if the patient experiences a traumatic fall or injury. However, Mrs. Tatum explained that when patients frequently visit the emergency room they can be discharged from hospice because they are not complying with the goals and ideals of hospice care. As discussed above, patients can also experience a live discharge if they stop declining and show indicators of improvement such as retaining the ability to engage in everyday

life. Mrs. Tatum explained that if patients can go “to grocery stores or [the patient is] able to keep up with housework” without being in pain then the discussion about live discharge can begin. While these actions are indicators of the need for hospice, there are special circumstances in which patients must engage in acts that would typically signal that they are a healthy individual.

During Mrs. Philips’ first enrollment in hospice care, her primary caregiver, Mrs. Miller, required a neck surgery that would prevent her from engaging in necessary caretaking. To ensure that her mother was receiving care, Mrs. Miller and her family decided to fly Mrs. Philips out to Florida to be taken care of by her son. The first hospice organization that Mrs. Philips was enrolled in labeled her trip to Florida as a vacation and consequently discharged her from their care. While this instance of disqualification is rare, it highlights the variability of qualification for hospice. Mrs. Miller’s own health situation forced her to move Mrs. Philips to Florida for a few weeks until she could once again take proper care of Mrs. Philips. The Millers were left to navigate finding a new hospice organization and re-entering hospice with a different organization due to the lack of clarity regarding disqualification under the Medicare hospice benefit. This lack of clarity in both qualification and disqualification processes create confusion that the patient-family unit is left to navigate on their own. Mrs. Miller’s experience highlights the gap in understanding between hospice organizations and patient-family units. The Millers took actions that they believed were best to ensure Mrs. Philips care, however because they unknowingly violated the hospice organizations policies they were no longer eligible for hospice care through that organization.

Hospice as a Business

The business model implemented by hospice organizations due to the Medicare hospice benefit has created an end-of-life care system in which there are considerable gaps that patient-family units must navigate with little to no resources. When family members accompany their loved one into hospice care they are doing so with a heavy weight on their shoulders. During the end-of-life period family members become responsible for their loved ones lives which produces stress and limits their ability to critically engage with the people and systems that are trying to assist them such as hospice care. Patient-family units lack a clarity regarding how to navigate hospice care. They often wrestle with difficulties such as the confusion about how, or if, their loved one will remain eligible for hospice. The lack of clarity about appropriate care actions can lead to family members trying to help their loved one by engaging in prohibited care acts to only realize later that these actions made navigating hospice care more difficult. These difficulties are a result of the gap in information between patient-family units and hospice organizations.

While hospice care is complicated to navigate, it has also become a deeply beloved service by the patient-family units who are beneficiaries. Even though hospice organizations are structured to be financially viable businesses, they continue to provide high-level personalized care to their patients which will be demonstrated in the coming chapters. The individuals who provide hospice care treat their patients as more than a dying individual. Each patient and their family members are seen as people with inherent value who deserve the best care that the team can provide for them. The approach to care creates a deep appreciation for hospice in the midst of confusion and gaps in navigability. Mrs. Miller expressed her appreciation for the 24/7 commitment to providing services that hospice has made available to both her mother and herself. “It's so wonderful… one time my mom fell through the night, and I called the main line

and they're always there. You call the main line and then they get out to the nurse on call, wherever they are, and they'll put you in and they'll come by your house. No matter what time. That is really nice if they get sick in the night or anything that you don't know what to do. They're there 24-7.” Mrs. Miller’s statement about having services available 24/7 gives insight into why hospice care is so deeply appreciated by its beneficiaries. Hospice care makes a commitment to the patient-family unit to support all of their needs around the clock. Hospice care sees the patient and their family members as one unit who needs to be cared for, and services extend beyond the physical care that is provided to the dying patient. Hospice care becomes a support system through which, the burden of care becomes lighter for the dying patient’s family. The lightening of burden produces a deep appreciation for care even when difficulties spring up within hospice care. Hospice care goes beyond biomedical care for the dying patient by providing holistic care for the patient-family unit.

Chapter 2 Beauty in Death and Peace in Departure

When I asked Mrs. Wells how she got involved in hospice care, she explained to me that she had previously worked at a hospital in a pediatric ICU unit where she witnessed the deaths of many children. After resigning from that position due to the emotional burden of watching children die, she never thought that she would find herself in spaces where death was inevitable. However, her experience with hospice care has transformed her understanding of death and what the process of dying can look like. Mrs. Wells explained her thoughts on death this way "I've actually just learned, I think, that there can actually be beauty in death and not just the sad, really depressing parts of it. I mean obviously death is always sad but dealing with elderly death now, and a lot of acceptance and people that have faith, or people that have lived really long lives, and just have this peace of outgoing… it feels a lot nicer." Mrs. Wells acknowledged that death was still difficult, and that she continued to be upset by her patients' deaths but working as a hospice nurse revealed a new way to die that involved beauty.

Mrs. Wells' understanding of death was transformed through the acts of care that she performs for people every day. Mrs. Wells can engage in these care acts and help people craft peaceful deaths because of the nature of hospice care. Hospice care is a holistic form of care, which means that it seeks to treat the patient as a whole person in which the intersection of the mind, body, spirit, and environmental factors come together to create a unique experience of death. Hospice care is rooted in biomedical care; however, it does not limit itself to the boundaries that biomedical care creates. Deborah Gordon explains that biomedical health care is guided by principles of naturalism and individualism (Gordon, 1988). Naturalism excludes spiritual explanations of how things came to be and believes that all things came from natural properties. Individualism refers to the prioritization of the individual over the group. In the

context of medicine, naturalism and individualism lead physicians to understand disease as a natural phenomenon that cannot be explained through spirituality, where the patient is evaluated as an individual instead of as a part of a larger social unit. Due to this, biomedicine sees health and disease as something to be defined by objective data instead of the experiences of the patient (Gordon, 1988: 25). Biomedical care operates under the assumption that death can be avoided because medicine is viewed as being outside of time and space through its dominance over nature (Gordon, 1988: 41). Due to this, biomedicine acts under the belief that any and every possible intervention should be taken because death can be avoided. While attempting to save patients from death is important, the commitment to interventions often results in experiences of death that are more traumatic than they would have been if there was an earlier acceptance of the inevitability of death.

Hospice care is a form of biomedical care that does not operate under the assumption that death can be avoided. Hospice care accepts that death is inevitable for everyone at some point and seeks to provide care in ways that make death more manageable and predicable for the patient-family unit. Hospice care has expanded beyond the boundaries of biomedical care practices and functions by operating outside of the belief that medicine can overcome nature and avoid death. With this understanding hospice care provides high quality affective care for the patient and their family members. Affective care practices are acts that are engaged in to attend to the emotional, spiritual, and relational needs of patients. Hospice care's holistic nature creates a kind of care that puts the patient and their priorities at the center. The care team's actions are motivated and led by the patients' needs and desires, not the diseases that affect them. Hospice care is a form of alternative care that creates better experiences of both end-of-life care and death itself.

Standard Biomedical Care and Hospice Care

Biomedical care is the health care ideology that we use in U.S., in which, understandings of the body, health, and disease are grounded in biochemistry and physiology. As Gordon explains, biomedicine understands "sickness as a natural phenomenon" which can be overcome by the power and knowledge of medicine (Gordon, 1988: 24). Biomedical care seeks to understand, prevent, and treat the body's ailments by focusing on the physical body of patients. Biomedicine often fails to consider the individual sociality and social environment of the patient and the structures that patients interact with, which influence the physical body's condition. Gordon explains that this occurs because medicine sees itself as being independent from "social, cultural, moral, and spiritual orders" and therefore unaffected by it (Gordon, 1988: 33). Biomedicine operates as if it can always overcome nature. The inevitability of death exposes the weakness of biomedicine's assumptions and guiding principles. During the end of life, biomedicine alone becomes a less helpful form of medical care. Hospice care is rooted in biomedical care; however, it simultaneously goes beyond the logics of biomedical care by not viewing death as something to fight, but a period in which intense care is needed most. Hospice uses the technological and medical advances of biomedicine to help patients while also providing affective care that helps the patient transition into death. In combining biomedical and affective care hospice care is an alternative form of medicine that extends beyond the confines of biomedical care.

Defining Care

Shirley Carter, a Heritage Care Hospice patient, had been receiving hospice care from Heritage Care Hospice for over a year for congestive heart failure. When asked about what

services Ms. Carter receives through hospice, she indicated acts such as wound care, showers, and assistance getting dressed. However, Ms. Carter didn't stop describing her care there. She told me about her deep relationship with her nurse aid and described herself as a "mentor" to the woman. Ms. Carter also spoke of the two volunteers that would come visit her. The volunteers were both in college and would tell Ms. Carter about their experiences at the local university. After graduating, one volunteer continued to reach out to Ms. Carter to tell her different experiences she had in her new job. When asked about hospice, Ms. Carter did not discuss the biomedical care that she received, such as medications, but instead focused on the aspects of care that demonstrated a relationship between herself and her care team. Both the nurse aide's commitment to caring for her body and the volunteer's commitment to forming a relationship was critical to the care that Ms. Carter received through hospice. Hospice workers provide care for their patients that goes beyond what their physical bodies need. Mrs. Carter needs assistance with showers and wound care for her body to be comfortable, however she also needs the emotional care that she receives through her companionship volunteers and the spiritual care that the chaplain can provide for her. To Mrs. Carter, each element of care was equally important because they all contributed to her well-being. Mrs. Carter's experience demonstrates the importance of expanding our understanding of what care is.

To further explore the full nature of care we can use Dalley's explanation of what care is in the context of community care. Dalley explains that part of care is "*caring for*" and "*caring about*" (Dalley, 1998) *Caring for* is an action and includes the acts that people engage in to make sure that people have what they need or want. *Caring about* is an emotion and refers to the feelings one has towards another person. Dalley explains that when providing care for someone, the caregiver can both *care for* and *care about* the person, however this is not always what

happens (Dalley, 1988: 8). Dalley's explanation of *caring for* and *caring about* highlights the importance of relationships in caregiving. To receive these kinds of care the patient has to be engaged in a relationship with their care provider. Through relationships, care providers not only *care for* but come to *care about* their patients. This understanding of care relationships is a central piece of what it means to provide holistic, patient-centered care. Mrs. Carter described being both *cared for* and *cared about* in her explanation of hospice care. She is *cared for* when she receives showers, wound care, and other physical treatments. Her care team demonstrates that they *care about* her by engaging in a relationship and sharing parts of their lives with her. Being *cared for* and *cared about* allows Mrs. Carter to experience holistic care.

Bowers et al. exemplify the complexity of what constitutes care in their study of nursing home residents through three conceptualizations of care: service, relating, and comfort. Care as service focused on the services that the residents received from the staff and largely lacked a relational aspect. Care as relating was centered on relationships where residents thought of themselves as taking an active role in their care and engaging in reciprocity. Care as comfort also involved relationships, however the relationship between caregiver and resident was seen as a way to ensure that the resident received assistance remaining comfortable in the painful stages of the end of life (Bowers et al. 2001). While standard biomedical care providers can, and often do, form relationships with their patients, the nature of the medical system insists that they identify and provide solutions to bodily ailments as efficiently as possible. This often eliminates the time it takes to form relationships with patients which results in better care. Hospice care can be experienced as service, relation, and comfort because the structure of hospice allows for relationships to be formed between the care team and the patient-family unit. Mrs. Carter's experience demonstrates the way that the hospice structure allows her to experience all three

forms of care; care as service (showers, wound care, etc.), care as relation (companionship visits), and care as comfort (ensuring that all her needs are met). Hospice expands our understanding of what care can be.

Cohn et al. expand the parameters for appropriate medical care by arguing that not intervening is an act of medical care. They explain that biomedicine is centered around interventions and behaviors that will cure, heal, or diminish the problems of the physical body. While these acts are important, the authors argue that "acts of inaction" require effort and expertise and are sometimes what the patient needs most. Therefore, it is important to include not acting in the concept of caring (Cohn et al., 2024: 6). Biomedical care has become the expectation when receiving healthcare services in the US. Hospitals, emergency clinics, and family doctors all provide medical services that are grounded in biomedicine and focused on specialties that inhibit the practice of holism. Sociologist Roi Livine explains that doctors are wired to view patients through their specialty training and seek to cure them instead of prioritizing making them comfortable (Livine, 2019: 28). If patients desire care that extends beyond the scope of biomedical practices, they must seek out this type of care themselves. Hospice care is a form of care that goes beyond biomedical care by expanding its understanding of care. While hospice caregivers are actively treating patients' symptoms, they simultaneously understand that not engaging in certain forms of care may be beneficial for their patients. Hospice care treats symptoms of the end of life but engages in "inaction" by not performing life-extending care. Instead of providing life extension, hospice care meets the social, emotional, and spiritual needs of patients.

The focus of biomedicine on interventions and cures means that care providers are primarily focused with prolonging the life of their patient instead of gauging when the patient

needs a different form of care. This can cause providers to lose sight of the person within the patient. When the person within the patient is lost there cannot be a relationship formed to allow care providers to *care about* their patients while simultaneously *caring for* them. Kaufman details this in her ethnography on dying in American hospitals. Kaufman explains that diseases are treated until there is nothing left to be done biomedically for the patient. When patients reached this point, death was the sole focus of the care providers. However, because biomedicine focuses on interventions and cures instead of the person within the patient, the care team was not able to provide the kinds of deaths that patients desired (Kaufman, 2005). The ability of biomedicine to provide care is halted when what the patient needs most is affective care instead of curative care. Cohn et al. found that when caregivers chose to just "be with" patients through acts, such as sitting with them, talking, or wiping their brows, they were engaging in medical acts that required effort and expertise. The palliative nurses' commitment to just being with patients was a valuable form of care (Cohn et al., 2024). Just being with patients is often not thought of as medical care because it does not provide an intervening act, however being with people is a form of relational care that is critical to *caring for* the whole person. In being with patients, care providers demonstrate that they *care about* the patient and that they are committed to their wellbeing even when there is nothing that biomedicine can do to extend their life.

While many Americans may prefer to die in hospitals while receiving biomedical care, hospice organizations provide a different experience that seeks to care for the whole person and their family members. Hospice care's structure allows care providers to engage in relationships with their patients and demonstrate *caring for* and *caring about* through the providers relational practices. The ability of hospice to *care for* and *care about* their patients demonstrates its ability to go beyond the confines of biomedicine. Biomedical care is restricted in its ability to provide

the totality of what it means to care because of their commitment to curing and intervening. Hospice is not bound by the expectation that curing, healing, and intervening is necessary or that it is what is best. Hospice care can identify the end-of-life period earlier than standard biomedical care and engage in practices that make dying a better experience for the patients and their families.

Hospice as Holistic Medicine

To be holistic means to account for all parts of the whole and to understand how each part is interconnected. Standard biomedical care is not holistic because of its commitment to mind-body dualism. Mind-body dualism is the idea that the mind and body are separate entities and should be treated as such. In Lorna Rhodes' article on biomedicine as a cultural system she explains that biomedicine is based on and perpetuates the idea of the separation of both the mind and body and nature and culture (Rhodes, 1998: 170). As discussed earlier, biomedicine is practiced with the logic that medicine and technology can overcome nature. Disease is understood to be a natural thing that can be overcome which results in the mind and culture receiving too little attention. In the context of the end of life, dying is a full-body experience. The mind cannot be separated from the body and while dying is natural, it also occurs in culturally specific ways. While hospice care is rooted in biomedicine it does not operate with the assumptions of mind-body dualism. Hospice care professionals seek to care for both the mind and the body of the patient as well as the family. In doing this, hospice care not only extends beyond biomedical care, but it becomes holistic care.

When discussing medicine, holistic health care starts from the presumption that the patient is comprised of multiple, interconnected parts. In their chapter on holistic healthcare for

intellectual and developmentally disabled people, Ventegodt et al. explain that "holistic healthcare is complete, or total patient care, that considers the physical, emotional, social, economic, and spiritual needs of the person, his or her response to illness, and the effect of the illness on the ability to meet self-care needs" (Ventegodt et al., 2016: 1935). Ventegodt et al. further explain that holistic care views people as being the union of "body, mind, spirit and the systems in which they live" (Ventegodt et al., 2016: 1936). The authors not only highlight the importance of the interconnectedness of the parts that make up people, but their positions within the systems that they inhabit. Holistic care prioritizes understanding the patient as a unique person who inhabits a specific role within structures of society. Furthermore, professionals practicing holistic care respond to the needs of the patient instead of treating the patient according to their illness (Ventegodt et al., 2016). In seeking to treat the person as an integrated whole, holistic care goes beyond the physical treatments that biomedicine provides.

Hospice organizations embody the ideals and practices of holistic healthcare through their interdisciplinary care teams. Mrs. Tate, a manager overseeing day-to day operations at Heritage Care Hospice, detailed the company's commitment to providing biomedical and affective care through interdisciplinary teams. Mrs. Tate described the biomedical care they provided, such as medications for patients regarding issues like general pain, respiratory distress, or secretions. Mrs. Tate further explained hospice and its affective care as "a lot of support and education" to ensure that no one dies alone. Interdisciplinary care teams allow for each aspect of the patients' needs to be met by highly qualified care givers. Each member of the interdisciplinary care team engages in forms of care that are not always biomedical, which are important to the total care of the whole person.

A hospice interdisciplinary care team consists of a physician, nurse, nurse aid, social worker, chaplain, and optional companionship volunteers. Physicians, nurses, and nurse aides are responsible for care practices such as taking vitals, administering medications, and identifying any medical health issues. While monitoring and responding to biomedical health issues are the main concern of physicians and nurses, they also engage in acts of care that are affective and are not required of them. When I talked to Heritage Care Hospice nurses, they described both engaging in expected acts of care, and in affective acts such as educating the patient-family unit, watching TV together, and engaging critically with patients about their experiences. The other half of the care team, the chaplain, social worker, and companionship volunteers, engage more explicitly in relational affective care practices. While these individuals cannot provide relief or comfort for physical sensations, they engage in acts of care to help the patient, and their family unit move through the process of dying. Social workers help patients navigate the difficult bureaucracy that hospice creates and is situated in. Chaplains engage with the patients' emotional and spiritual wellbeing to ensure that the patient-family unit is adjusting to each change that occurs throughout the end-of-life process. While companionship volunteers are often not privy to the health information of patients, they provide critical social interaction that is often lost when people begin to actively die. Each part of the care team can engage with the patient and satisfy their interconnected needs. When talking with Mrs. Jones, a hospice nurse, about the importance of the different roles within hospice care she stated that "without the entire team I don't think we have as much of an impact…it provides a very specialized care that makes people feel like there's somebody there for them at the very end." Mrs. Jones' statement highlights the impact that the interdisciplinary care team has on their patients, while also expressing the ability of the care team to engage in affective care that is relation based and shows people that they are both

cared for and *cared about*. Each member of the hospice interdisciplinary care team engages in acts of affective care that create an experience of care that goes beyond standard biomedicine.

Biomedical care is critical, and should not be disregarded, or its importance downplayed, however when biomedical care is combined with affective care and a holistic approach, the effects of care are much greater than one form of care by itself. Hospice has developed as a holistic medical care practice that goes beyond what biomedical care can offer. One of the most critical parts of hospice care's ability to go beyond biomedical care is its commitment to affective care by all members of the care team.

Affective Care in Hospice

What is Affective Care

Affective care goes beyond the needs of the physical body to provide care for the mental, spiritual, and relational parts of patients. Affective care involves being present, listening, and engaging in acts of comfort and empathy. When I asked Mrs. Lambert, the daughter of one of my hospice companionship patients, how she would describe hospice care she began explaining how Heritage Care Hospice has its own "medical director…nursing staff...CNA'S… [and] outreach." After a pause she said, "I don't know, to me, it's just like all-encompassing and full wraparound services." In thinking about her father's experience with hospice, Mrs. Lambert highlighted not only the medical benefits that her father received, but also the affective care that his hospice team engaged in, such as the birthday present that the volunteer coordinator prepared and had delivered to Mr. Graham. Mrs. Lambert's use of the words "all-encompassing" and "wraparound service" helps us to begin thinking about what affective care is and how it

contributes to hospice organization's ability to provide care that goes beyond standard biomedicine.

The Importance of Relationships

In the attempt to provide holistic care to their patients, the relationship between the hospice care team and the patient is critical. Hospice care seeks to establish a relationship with the patient and their family before the active dying process begins. However, some patients are not able to enroll in hospice care until after the active dying period begins. While talking to Mrs. Rodgers, a Heritage Care Hospice nurse, she explained that hospice is most beneficial before the active dying period. Mrs. Rodgers described engaging in practices that helped the patient-family unit to deal with the process of dying. When patients were what she called "imminent" Mrs. Rodgers believed that hospice could help them, but that it was "too late" to do the deep emotional and educational work that she engaged in with other patients.

When patients entered hospice care before the active dying period, they were able to start their care experience by establishing a relationship with their care team. Mrs. Wells described her experience of establishing a care team that fit the personality of their patient perfectly. When Mrs. Wells first began visiting this patient, she was intentional about sharing important parts of what defined her, such as how she owned a little farm and all the animals she raised. The patient was very excited that he "got a country girl" and asked Mrs. Wells to come more frequently. In addition to Mrs. Wells, the patient's nurse aid was also a "country girl" and would sing to him while she gave him showers. Mrs. Wells explained that the patient would even pull out his guitar and sing with the women. Mrs. Wells described the patient's care team as "the perfect setup" for his personality and preferences. While not every hospice patient will experience "the perfect setup," this example demonstrates the effort that the hospice care team expends in establishing

relationships with their patients. Mrs. Wells chose to share parts of herself that she was not required to share. She easily could have met the patient and only addressed his physical needs, but instead she engaged in affective care by establishing a relationship with the patient. In doing this she was able to connect on a more intimate level with him and demonstrate that she would *care for* and *about him*. Mrs. Wells and the nurse aid went above the call of standard biomedical care to provide holistic care for their patient.

Mrs. Wells' experience highlights the importance of relationships for affective caring. Under special circumstances the patient-caregiver relationship can be thought of as familial. Berdes and Eckert explore the use of family metaphors by nurse aides in nursing homes who are often confronted with racist speech from the residents that they care for. The racist speech most often occurred when residents referred to the nurse aides by terms that are considered unacceptable today. Berdes and Eckert explain that the nurse aides were able to continue providing quality care for their patients because the affective care that they provided "offset their experiences of racism" (Berdes and Eckert, 2007:340). The authors describe affective care as the foundation for all other kinds of care because affective care provided the motivation for the aides to engage in quality technical care. The aides described the care they provided in relation to the kinds of care that they would provide for their own family members. Even when patients engaged in racist behaviors, the aides chose to engage in boundary work which separated the residents from their racist behaviors. This allowed the aides to form deep relationships, which resembled familial relationships, and provide affective care (Berdes and Eckert, 2007). To provide quality technical care the nurse aides had to first form relationships which allowed them to *care about* their patients while simultaneously *caring for* them. Berdes and Eckert explain that affective care isn't a byproduct of technical care, it is what allows quality technical care to occur

(Berdes and Eckert, 2007: 347). While the nurses at Heritage Care Hospice never described encountering racists patients, they did speak about their patients in ways that highlighted the deep relationships they had formed. The nurses at Heritage Care Hospice chose to engage with their patients in ways that resembled familial relationships.

Enacting Affective Care

As exemplified by Mrs. Wells' story, establishing relationships is critical to the enactment of affective care by hospice care teams. Relationships begin to translate into holistic care through affective care acts. Mrs. Jones, a hospice nurse, illuminated this embodiment of holistic care when describing the actions of members of the care team who were not medically trained. Mrs. Jones explained that one of Heritage Care Hospice's social workers would go and "clean their [the patients] house or organize things for them" when they didn't need her assistance with legal aspects of hospice care. Cleaning and organizing is not an expected act of care for hospice social workers but occurs due to the relationships that are formed while providing expected acts of care. Mrs. Jones further described acts of affective care such as the practice of making the family members pinky fingerprint keychains that serve as "a pinky promises that [the patient will] always be there to love them." The relationships that are formed by the care team extend to the family members of the dying patient. There is a deep commitment to provide care to the patient-family unit in a way that does more than soothe the physical effects of the dying process for the hospice patient. In Buch's review of the anthropology of aging and care she conceptualizes care as being both "resource and relational practice," where the acts of care are dependent upon who is caring, and who the receiver of such care is, and the institutions that shape that dynamic (Buch, 2015a: 279). Mrs. Jones' examples highlight the relational practice of caring. The social worker not only provided a resource for the families through her services as a social worker, but

she engaged in care as a relational practice by cleaning their houses and creating the pinky finger key chains.

Bowers et al. highlighted the different ways that patients conceptualized quality care. The resident group that explained quality care as relational emphasized the importance of their nurse aides sharing personal information and engaging in active listening (Bowers et al. 2001). As Mrs. Wells demonstrated, sharing personal information allows care providers to engage in a level of care that is only available through an established relationship and trust that the caregiver *cares about* the patient. The aides that were thought to be the best were those that engaged in reciprocal sharing where they listened to and later remembered the character traits and preferences that the patients shared with them. The authors explain that in doing this "the aides were acknowledging resident selves other than those related to old age, illness, and disability" (Bower et al., 2001: 542). In acknowledging a self beyond old age, caregivers are forming relationships with their patients that go beyond the patient's physical care needs. Knowing the patient's personality and preferences allows the caregiver to engage in care acts that show the patient that the care giver *cares about* and *cares for* them. Additionally, these acts help the patient to hold onto a sense of self outside of being a dying individual.

Hospice nurses at Heritage Care Hospice engaged with their patients in ways that indicated that they saw the patient as more than a dying person through affective care acts that re-affirmed that the patients were still themselves. Mrs. Jones described what she called a few of the "social aspects of caring for people" when describing a typical day of work. One patient of hers loved lying on the couch and watching TV, so Mrs. Jones would go in and just "be with" her patient by snuggling her and massaging her arms. Another one of her patients wanted to "have a tea party and…get dressed up in her big hat," so Mrs. Jones helped throw a tea party for the

woman. Mrs. Jones described these care acts as getting to "fall in love with people every day." Hospice nurses begin their care work by establishing relationships with their patients where they explore who the patient is, what they expect from their care, and what their desires are in dying. After establishing these things, the nurses can engage in personalized acts of affective care that provide the patients with comfort, relationship, and relief from pain. The inter-personal care that the care team engages in creates an environment that prioritizes the patient and their experience. In doing this, the type and level of care that is provided extends beyond biomedical care.

Mrs. Jones' examples of affective care are just a few examples of what affective care can look like. Acts of affective care in hospice include educating patients and giving them tools to navigate through confusing aspects of end-of-life care. In talking about her experiences of providing help for family members of dying patients Mrs. Rodgers explained that families come in with differing levels of knowledge about the processes of death based on previous experiences. After the dying patient is enrolled in hospice, the family receives a pamphlet titled "Gone From My Sight," which plainly lays out common changes that the dying individual will experience from three months to minutes before death. Mrs. Rodgers explained that "every time we [nurses] go, we'll kind of see where their knowledge is lacking or where they might need some more information to sort of alleviate their fears or help the patient." The processes of dying are often unknown to both the patient and the family members which can make death a more scary and uncomfortable process. Mrs. Rodgers and other hospice nurses seek to engage in constant acts of care to ensure that the patient-family unit experiences death in the best possible way. In Lappe's article on holistic health, he describes the holistic health provider as a "helper and information giver rather than a cryptic, medicine dispenser" (Lappe, 1979: 478). Lappe's claim exemplifies the way that holistic health care organizations go beyond biomedical care and

take on more all-encompassing roles. Through education, hospice nurses are helping to alleviate fear and uncertainty which provides affective care to the patient-family unit.

Affective care in hospice can involve assistance navigating the bureaucratic systems that structure hospice care. When describing the role of social workers within Heritage Care Hospice, Mrs. Tate explained that the social workers will often assist patients with filling out applications for services such as "meals on wheels," "sitter services," or "disability services." While the patient-family unit is ultimately responsible for the completion of these applications, social workers can provide guidance and assistance to the families to ensure that they have all the services necessary to navigate the end of life. This is a form of affective care that is produced from the interdisciplinary team and a commitment to serving all the needs of patients. As discussed in the previous chapter, navigating the structure of hospice is confusing and can create gaps of understanding for patient-family units. Having a social worker who can help with this navigation provides a form of affective care to the patient-family unit.

Mrs. Lambert's experience with a hospice social worker demonstrates the affective care that is engaged in by the care team. Her father, Mr. Graham had been taking anti-rejection medication for years after a successful liver transplant, however when he was enrolled in hospice, insurance no longer covered the cost for the life-prolonging medication. Unsure of what to do, Mrs. Lambert contacted her father's case worker and explained their situation. The case worker was able to contact pharmacies and explain to Mrs. Lambert that because the medication was considered life-prolonging, insurance would no longer pay for it. Mr. Graham's social worker helped Mrs. Lambert discontinue the medication. While this act of care is part of the typical responsibility of social workers, Mrs. Lambert expressed her appreciation for not having "to mess with any of it, which was beautiful." Her experience navigating the hospice care system

with the help of the social worker led Mrs. Lambert to explain that hospice has "exceeded expectations."

Mrs. Rodgers explained that Heritage Care Hospice's mission is to ensure that a patient is never alone in their dying process. This is achieved through acts that ensure physical health and acts that are constituted as just "being with" the patient as they move through the processes of death. Hospice goes beyond the confines of biomedical care in its commitment to providing high quality affective care. The affective care of hospice organizations results in patient-centered care that cultivates choice, which creates the ability to be an actor instead of one who is acted upon.

Hospice as Patient-Centered Care and the Importance of Choice

Patient-centered care refers to health care practices that prioritize the patient's needs and desires first. Patient-centered care requires care givers to engage with patients in conversations about their current experiences and future desires. Engaging in patient-centered care is a way to enact affective care and allow dying patients to craft their death experience to be what they desire.

Mrs. Baker, the sister of a Heritage Care Hospice patient, demonstrated patient-centered care in the story of her ex-mother-in-law's death. Mrs. Baker and the rest of the family were at the bedside of her ex-mother-in-law who was hospitalized. The medical staff had concluded that the best thing they could do for the patient was to stop medication, food, and water. Mrs. Baker explained that her ex-mother-in-law was actively "leaving," but the daughter, Susie, was having a difficult time watching her mother pass away. Mrs. Baker described Susie "pounding on her mother's chest" and telling her "You can't leave." Susie continued doing this and began yelling at the nurses to not let her mother die. Mrs. Baker explained that the hospice nurse "very gently

put her arms around her, put her hands on top of her hands." The hospice nurse's reaction stopped Susie from continuing to beat on her mother's chest and cry out. The hospice nurse held Susie in her arms while her mother passed away. Mrs. Baker explained the hospice nurse's actions as "giv[ing] [the mother] what she needed by taking care of her daughter." Mrs. Baker's story exemplifies person-centered care through affective acts. The hospice nurse understood what kind of death the patient desired and was able to step in when the desired death was at risk. Furthermore, the hospice nurse was able to provide affective care to the daughter by holding and comforting her in the immense grief that she was experiencing. Mrs. Baker's story powerfully demonstrates the importance of patient-centered care and affective acts in the end of life. The holistic perspective of hospice care enabled the nurse to engage with the patient-family unit in a way that resulted in a good death.

Patient-centered care also involves the ability of patients to make choices. Mrs. Wells described the conversations that she engages in with her patients which allows her to perform patient-centered care. Mrs. Wells asks patients to describe how they picture their death, including who they want there, the quality of life they expect, and their desires relating to pain and medication. In doing this, Mrs. Wells is creating an opportunity for her patients to make choices about the end of their lives which will guide how she provides care. Mrs. Wells engages in these conversations so that she can provide tailored affective and biomedical care to her patients. Both Mrs. Jones and Mrs. Rodgers explained the way that they tailor visit schedules to the preferences of their patients. The nurses will coordinate their schedules so that they are able to meet the patients' needs and desires relating to their care. The acts of care that hospice nurses engage in prioritize the patient-family unit which allows caregivers to provide high level affective care.

Bowers et al. detail the importance of having the ability to make choices in environments that are safe and promote independence (Bowers et al., 2001: 540). In her book on collective caring Dalley further builds on the importance of choice. Good care must allow the patient to "be responsible for his or her life choices." Of equal importance, Dalley states that the "system of care should be responsive to the needs and inclinations of the individuals receiving care" (Dalley, 1988: 115). These scholars highlight the importance of choice in quality care. To perform person-centered care in health care, the organization must create opportunities for patients to express their desires and then respond to what was expressed. The hospice nurses that I talked to each described ways that they engaged in person-centered care by listening to and responding to patient's wishes.

New Health Care Possibilities through Hospice as Alternative Care

Hospice care is situated alongside biomedicine but extends beyond the reaches of biomedicine through its holistic nature. Hospice understands dying patients as individuals who embody particular social roles within societal structures. Hospice care sees the patient as an individual who has physical, emotional, and spiritual needs that must continue to be met throughout the dying process. Hospice care professionals position themselves to provide for all the patient's needs through affective care practices. It is through affective care practices that patient-centered care in hospice occurs. Hospice care's ability to engage in patient-centered care results in affective care that goes beyond what biomedicine can provide.

When health care accepts the inevitability of death and takes a holistic approach to patients, death is transformed into a manageable process instead of something to be combated. Knowing that death cannot be escaped, hospice prioritizes how patients wish to experience

death. Hospice care creates a space where choices are available for patients whose agency is being limited. Through the availability of choice, patients can engage in acts that assist them in maintaining their personhood. The holistic nature of hospice care can lead to an experience of healing that extends far beyond the biomedical conceptions of healing. To understand the possibilities that are opened for patients through hospice care, it is essential to understand it as a form of care that goes beyond the boundaries of biomedical care. In going beyond the boundaries of biomedicine hospice becomes personhood care where new experiences of healing are made available.

Chapter 3 Retaining Personhood Through Hospice Care

Mrs. Stone was one of the first hospice patients to whom I was assigned to provide companionship. As explained in the introduction, Mrs. Stone was a joyful woman who enjoyed the company of the other women that she was surrounded by at Creekside Assisted Living Facility. For the first two months of my volunteer experience, I went to see Mrs. Stone every two weeks and often chose to see her during lunch time so I could talk with her tablemates as well. Mrs. Stone passed away about three weeks after a serious fall that left her in a great deal of pain. Throughout the time that I visited Mrs. Stone I noticed that she didn't seem to lose who she was as a person during the end of her life. Mrs. Stone had been a woman of faith before she needed hospice care and was able to retain her faith throughout her last days. While I did not know Mrs. Stone for very long, when I did visit her, she maintained a neat physical appearance. She kept her hair long and always had it nicely brushed, her clothes were always coordinated, and she kept her living space tidy. Mrs. Stone's physical appearance remained largely the same until the day of her death. Unlike some of the other residents, Mrs. Stone remained engaged in meaningful social interactions until her fall which subsequently inhibited her ability to engage with other residents. At the time I believed Mrs. Stone to be one of the lucky few to experience a death where she was able to retain most of her personhood. To an extent I do still believe that she was lucky, however I also know now that hospice care played a significant role in Mrs. Stone's ability to retain her personhood throughout the process of dying.

Modern medicine in the U.S. is focused on the physician and the symptoms of a disease. While hospice care is medical care, it involves more than the highly medicalized and professionalized process that occurs in other health care systems. The holistic care provided by hospice prioritizes the patient-family unit's needs, which allows hospice caregivers to engage

with individuals in ways that recognize them as full persons. Through this kind of engagement with patient-family units, hospice care is personhood care. Through hospice, both the patient and their families can receive personhood-affirming care that makes both the dying and grieving processes more manageable.

Personhood

To understand hospice care as personhood care we need to tease apart the complicated meanings of personhood. What qualifies someone has having personhood is subjective depending on the cultural world that a person inhabits. This has resulted in many varying definitions of personhood which have overlapping qualities, but do not result in a single definition of personhood. For the purpose of this chapter, I have attempted to define personhood within the context of Oklahoma hospice care. Personhood in its simplest sense means being a living human being. The complexity of defining personhood emerges when we attempt to nail down what it means to be a full person experiencing full personhood within a particular cultural understanding and set of practices. Having full personhood goes beyond the biological qualities that make someone human. Being born makes someone a person with personhood, but it does not guarantee full personhood. Personhood is deeply tied to an individual's sense of self. Part of the experience of full personhood is having a sense of who you are. When changes occur to a person, physical, relational, or psychological, their sense of self is altered because we define ourselves in in relation to the things that we interact with. During the end-of-life individuals experience a variety of changes that alter their sense of self. When a person's sense of self is no longer stable their personhood also feels threatened. A sense of oneself is critical to full personhood. In addition to this I have chosen to think through the complexities of what

personhood means and how it is experienced in the end of life through the body, agency, and social networks.

Tine Gammeltoft's ethnography *Haunting Images* helps us to better understand this idea. Gammeltoft details the difficult reproductive decisions that families in Hanoi, Vietnam, face due to the detrimental health issues caused by the use of Agent Orange during the Vietnam War. Vietnamese women frequently experience pregnancies with a variety of abnormalities. If the pregnancies were carried to term the infant would have severe disabilities that would require members of the family to provide intensive lifetime care. These women and their families most often opt for abortions when they conclude that the disabilities of the fetus would prevent the child from attaining full personhood. In this context, full personhood includes the ability to engage in ancestor worship, be integrated into the community, and engage with the world around them in a productive manner (Gammeltoft, 2014). Gammeltoft's ethnography helps us to understand that full personhood is not something that is inherent but is rather something that is engaged in throughout one's life in each cultural context.

Another way to think about personhood is that it is the set of practices, goals, and life experiences that define who we are as individuals and how we form a sense of self. We are all born with some degree of personhood just by the nature of being humans, however, to be recognized as a full person, by ourselves and others, we must engage in activities that keep us connected to things of this world such as people, objects, social structures, or other entities. It is through connections within the world that we are able to engage in practices, goals, and experiences that define us as persons. In the context of Gammeltoft's ethnography, the important things of the world were ancestor worship, integration into the community, and the ability to engage with the world productively. In another context, anthropologist Elana Buch explores the

connection between homes and personhood among older Chicagoans. She explains that older Chicagoans actively try to remain in their homes even when they need intensive help because they connect their social personhood to their home. Some transformations in personhood were resisted by continuing to live in their personal homes (Buch, 2015b). Buch's work helps us expand our understanding of the importance of being connected to the world around us. In Buch's work these connections tie a person to a time when they were recognized as a full person by themselves and those around them. Full personhood in the American context is about connections to things defined as culturally important,

While personhood care is not the explicit aim of hospice organizations, it is a byproduct of their commitment to holistic care that prioritizes the patient-family unit's needs. Full personhood is a subjectively defined concept. Through my research I came to think about full personhood as being expressed through the body, attained by acts of agency, and appears to be lost when a person's social network is diminished. An important part of full personhood is the way that an individual conceptualizes of themselves. Throughout life individuals create a sense of themselves which is challenged during the end of life. When our sense of self is forcibly altered, we experience a change in our body's ability to enact agency and engage in social networks. Each of these changes contributes to the feeling of lost personhood. Hospice care professionals work to allow the patient-family units to continue experiencing full personhood through the continued use of their bodies, ability to engage in decision making, and a commitment to relational care that promotes social networks. To better understand how hospice care works to maintain full personhood of the patient, it is necessary to first explore how full personhood seems slip away during the end-of-life period.

The Body

The body is a medium, through which, the world influences the personhood of an individual, while also being the medium through which individual personhood is expressed. The body therefore both receives input towards the development and maintenance of personhood and is a canvas on which personhood is expressed. Our body is what allows us to engage in practices, goals, and life experiences. It is through these three things that the body receives input for our sense of self which contributes to the experience of full personhood. During the end-of-life the body undergoes dramatic changes which limit a person's abilities such as a difficulty walking, talking, or engaging in acts like driving. When these abilities disappear, or are taken away, a person experiences a change to their sense of self. The abilities that previously helped a person define themselves and experience full personhood are no longer available to them. In processing the loss of certain bodily abilities, dying individuals often experience a diminishment of full personhood. This was demonstrated to me in an interview with a hospice patient that I provided companionship care for named Margret Dean. Mrs. Dean resided in an assisted living facility in Norman, Creekside Assisted living Facility, whose residents and staff were predominantly women. Mrs. Dean retained a high level of cognitive functioning but was bound to a wheelchair which limited her ability to move within and outside of the facility. Mrs. Dean was well liked by the staff and other residents and was always looking to provide help or friendship to other residents at the facility. Over the months that I visited Mrs. Dean we developed a friendship and visit routine in which we would briefly talk about our lives and then I would read a book to her until I needed to leave that day. While Mrs. Dean and I had a friendship, she had never shared with me her experiences of hospice care and aging. Throughout most of our interview Mrs. Dean was in her bed and faced the wall or looked up at the ceiling. This behavior was quite unlike her,

as she typically had an engaged and relaxed body language in my presence. She focused her narrative mostly on her experiences with intimate relationships and how she entered the living facility she resided in. At the end of the interview, I asked Mrs. Dean if there was anything else she wanted to share with me. She quickly looked at me and stated, "I was always very promiscuous." Taken aback I paused for a second and asked if this sexual behavior had occurred before she entered her living facility or while she lived there. She clarified that the sexual behaviors she was referring to had occurred before entering the living facility. Mrs. Dean stated "if I could do it now, I would. If I knew anybody who wanted to do it." I asked Mrs. Dean if she felt like her living facility kept her from fulfilling her sexual desires to which she responded that "being 80 years old" kept her from having sex, but that there was also no one at the facility to do anything with. Shortly after I ended our interview a male nurse entered her room and adjust her bed to be more comfortable. After he exited the room, she told me frankly that she though he was attractive and would be promiscuous with him if she could. I giggled and told Mrs. Dean that she was funny to which she told me that she was just being honest about how she felt.

In thinking of the body as a medium for expressing personhood we can understand how personhood is altered when people are no longer able to engage in the abilities that allow them to express their full personhood. In her ethnography on Hospice in the UK, Julia Lawton discusses the importance of bodily capacities for the expression [or realization] of selfhood. She explains that when bodily capacities such as being a bounded body, or the ability to act as an agent of embodied action are lost, then the realization and maintenance of selfhood slips aways (Lawton, 2000: 7).[2] To be a person then means that the individual must retain bodily capacities and

[2] I want to note that this discussion about bodily abilities is in reference to individuals who experienced a loss in ability. Individuals who have experienced physical disabilities from birth have a different experience than those who could previously engage in the lost ability. It is the loss of a previous ability that impacts a dying individual's experience of full personhood.

abilities which mark them as a person both to themselves and to other people around them. When these capacities and abilities begin to slip or are taken away from the dying individual, their relationship to full personhood becomes unstable. Lawton further explains that when hospice patients experience a loss of mobility, they simultaneously experience a loss of self because they no longer retain the same bodily capacities and abilities they once had (Lawton, 2000: 10). Lawton's analysis helps us to understand Mrs. Dean's experience with a deteriorating body which contributed to her incapacity to engage in previously valued abilities. Before experiencing a physical decline and entering the facility, Mrs. Dean understood part of her sense of self to be connected to her ability to engage in sexually intimate acts. With this ability no longer available to her, her sense of self was altered, and she struggled to define herself and experience full personhood as she previously had. While Mrs. Dean still manages to engage in meaningful connections with people, her status as being at the end of her life has altered her ability to use her body in the ways that previously contributed to her sense of self.

Elly Teman's ethnography, *Birthing a Mother,* illustrates the importance of the body to our understandings of what it means to be an individual with personhood and sense of self. Teman focuses on Israeli women who are undergoing processes of surrogacy. While pregnancy is a very different bodily experience than dying, it involves dramatic changes to the body which alter women's sense of self and understanding of personhood. In the case of surrogacy as described by Teman, the body plays a significant role in the ability of surrogates to maintain a sense of self that is separate from that of the intended (contracting) mother. Teman explains that surrogates use a concept she calls "body mapping" to separate portions of the body that they associate with themselves from body parts that they associate with the intended mother and fetus. For surrogate women, the womb is conceptualized as being separate from the rest of the body

and as a part of the intended mother's body. Surrogate women think of their hearts and eggs as being core to their identities and therefore are not separated from the body in the same way that the womb is. This separation allows the surrogates to distance themselves from the pregnancy to prevent forming an attachment to the fetus and to maintain their separate personhood and sense of self while engaging in dramatic bodily changes (Teman, 2010). Teman's example demonstrates the way that developing a particular conception of the body can create a different understanding of personhood. Importantly, these women were able to separate their body's ability to carry a pregnancy from their sense of self which allowed them to continue experiencing full personhood. The women in Teman's ethnography were not at risk for not being recognized as full persons like dying individuals are. However, her ethnography importantly demonstrates the ability to develop tools and practices that contribute to the maintenance of a desired personhood. In the context of hospice care, most patients do not want to lose their recognition as a full person. To maintain full personhood, they engage in activities and make use of tools to retain their personhood. Hospice care's holistic, personalized approach to care is a tool which allows individuals to continue to use their bodies to express full personhood.

Agency and Personhood

Agency much like the body, is a critical part of achieving and retaining personhood. The body is the medium through which personhood is crafted and expressed while acts of agency are manifestations of full personhood. Agency refers to the ability to act and make changes in the world. An act of agency can have a physical effect such as moving an object, or agency can be carried out in the conceptual sense of being able to influence the world around you. All enactments of agency are important to the achievement and maintenance of personhood. During the end of life in standard biomedical care, patients may feel as if they have lost the ability to

enact agency. The hospital and biomedical care setting restricts patients' abilities to act on the choices that they want to make. In Julia Lawton's ethnography of personhood and agency, she explains that personhood depends on agency which is the ability to act for oneself (Lawton, 200:101). It seems that personhood cannot be experienced if an individual is not able to engage in acts of agency in either the physical or conceptual sense. Lawton further explains agency as the "fusion of mind and body, self and action" (Lawton, 2000: 108). Lawton's explanation highlights the importance of the body in being able to carry out and express desires of the mind and the self. To be an agent in the world means that a person can make a decision and act to see that decision create a result.

As individuals age, or the effects of terminal diseases progress, they experience a decreased ability to engage in acts of agency due to the restrictions on what they can do for themselves. This decreased ability to engage in acts of agency can be caused by things such as the bodily deterioration that erodes the expression of personhood, being forced to enter spaces where decision making opportunities are limited (such as assisted living facilities), or the perception of others that a person is no longer capable of making their own decisions (typical of how elders are viewed). As Lawton explains, the loss of the ability to act as an agent of embodied actions creates a loss of the self (Lawton, 2000: 100).

The processes by which and spaces where aging and terminal disease occur are marked by gradual losses of personhood due to the inability to engage in acts of agency. This was first demonstrated to me in a conversation I had with a man in Mountain Top Assisted Living Facility. While doing hospice volunteer visits I found that I really enjoyed visiting one of my patients, James Graham, during lunch time as this gave me the opportunity to sit at his table and chat with his tablemates about whatever they pleased. One of Mr. Graham's tablemates was a man named

John-Brian Johnston. Mr. Johnston was a spirited man who often vocalized his dissatisfaction with the living experience within Mountain Top Assisted Living Facility. While I was sitting at lunch with the men I asked if there was anything fun planned for today. I often asked this question, and most of the time the men responded with frustration that there would be nothing to do. This time when I asked, Mr. Johnston handed me a sheet of paper that had a word puzzle on one side and the activities for the day on the other. The activities included things such as bingo, karaoke, and other games often associated with elderly people. Not seeing a problem with this list, I told Mr. Johnston that karaoke would be fun. He responded quickly that the songs would be "Donald Duck songs" which I took to mean children's songs and therefore not a song Mr. Johnston would be interested in singing. He continued explaining that all the activities were for women. Mr. Johnston wanted to be able to build things and use tools as he had done before he came to live at Mountain Top.

Mr. Johnston's dissatisfaction with the activities he was offered is an example of a loss of agency that contributed to a diminishment of full personhood because of the severed ability to connect to objects and activities that were meaningful to him. The space that Mr. Johnston was obliged to live in due to his terminal disease was one that severely limited his ability to choose his daily activities. In a discussion with the volunteer coordinator of Heritage Care Hospice I explained what Mr. Johnston had told me, to which she responded that it was too dangerous to allow the residents to use tools and build things like they used to. Mr. Johnston was no longer able to create and fashion himself as a man who could use his body and mind to create objects. His inability to make a choice without hinderance and act on that choice resulted in a diminishment of his full personhood. This was compounded by the way that the facility and hospice staff conceptualized the residents as being too fragile and unable to engage in these

activities. For the facility's staff the health and safety of the body was more important than the expression of personhood.

When individuals enter spaces or times when their full personhood status is seemingly unstable or weakening, other people have a hand in determining if the person qualifies for full personhood. In Sharon Kaufman's ethnography on dying in American hospitals she discusses the difficult decisions that family members and the care team must engage in when life-prolonging care is being given. In her ethnography, Kaufman details the idea that in our society a person is understood as being able to "create and fashion the self," therefore when a person can no longer express important ideas about how they create and fashion themselves they are no longer seen as having a meaningful life by those around them (Kaufman, 2005: 293). When the care team recognizes that a patient will never be able to be taken off a respirator and continue fashioning and expressing themselves, they urge the family to remove the life-prolonging care because the person they once knew no longer exists (Kaufman, 2005). Using Kaufman's example, we can see how agency is crucial to the creation and maintenance of personhood. If agency is the ability to act on our desires, then when individuals lose the ability to engage in decision making, their ability to enact full personhood is restricted. In Mr. Johnston's experience, the inability to make decisions about recreational activities and act on those decisions restricted his ability to express his full personhood. Being a full person means being able to make meaningful connections to the entities around you. For Mr. Johnston a meaningful connection would have involved using tools to craft new objects. The restriction of his agency by others, for the purpose of protecting his body, resulted in the diminishment of his full personhood.

Social Networks and Personhood

As we have explored thus far, personhood requires acts of agency that express the desires of the individual through the body, however, if the individual is not properly enmeshed in social relationships there cannot be full personhood. The achievement and maintenance of personhood requires meaningful and sustained social relationships in which the individual engages in expected social requirements. The loss of social relations and resulting social death was demonstrated by Mr. Graham. In an interview with Mr. Graham's daughter, Mrs. Lambert, she described the dementia her father was experiencing. He struggled to remember his family members and engage in meaningful conversation with people around him. His dementia meant that he often forgot the things that he had just experienced. Furthermore, his dementia often led to Mr. Graham making hurtful comments to his daughter without realizing that he was hurting her feelings. Mr. Graham's dementia altered his ability to engage in practices, goals, and experiences which led to a perception by his family members that he was no longer the same person. In discussing how Mrs. Lambert dealt with this experience, she explained that she would tell herself that her dad's brain was broken and that he wasn't who he used to be. Mrs. Lambert explained that her father was no longer able to engage in social interaction the way he used to which had caused the loss of a social network that made Mr. Graham who he was. Mr. Graham's dementia kept him from being able to recognize this social death, but the people around him could recognize it, which changed the way they interacted with him. While Mr. Graham hadn't completely lost his social network, he had lost his ability to meaningfully engage with people in his network, which produced a diminishment of full personhood.

The experiences of aging and disease seem to transform individual's sense of self and ability to enact full personhood. The body deteriorates and limits the way that people can express

their inward selves, opportunities to enact agency are reduced due to the spaces and conceptualizations of elderly and sick individuals, and social networks seem to slip away until the dying person is left with a diminished personhood. In his chapter on the duty of children to care for their parents with Alzheimer's, Daniel Callahan thinks of these parents as being socially dead individuals. According to Callahan, social death occurs when the person no longer has the ability to "recognize others, to talk, to feed herself, or have interaction with others" (Callahan, 2015:156). Callahan demonstrates the importance of both bodily actions and the social element of personhood. Taking Mr. Graham as an example, his difficulty to continue to engage in his previous social network resulted in social death in which he no longer consistently remembered the important people from his life.

Lawton further highlights the importance of social relationships in her chapter on the social death of hospice patients. She explains that as a person ages their "social and temporal perceptions" no longer align with those in their social networks, which hinders family and friends' ability to empathize and take part in meaningful social engagements. This loss of social relationships can contribute to the loss of the self (Lawton, 2000: 148). The social networks that people are (or are not) able to engage in help to construct personhood though giving people the ability to be agents in others' lives and express their personhood through the body in social interactions. Without the social network, the person can struggle to engage in meaningful connections that assist in expressing full personhood.

While Callahan and Lawton discuss the loss of personhood due to diminished social networks Janelle Taylor explores the way that people retain part of their personhood by continuing acts of care. Taylor describes her experiences caring for her mother with dementia, in which she explains that other people often gauged the progression of the disease by whether her

mother could recognize her and remember her name. The inability to recognize someone or remember who they are often marks the time when other people stop recognizing the individual with dementia as a full social person, as Calahan and Lawton demonstrate. Importantly, Taylor argues that even when individuals cannot recognize or remember you, they continue to do the acts of care that they engaged in before dementia (Taylor, 2008). At the time of our interview Mr. Graham could only inconsistently recognize people and remember their names. The difficulty that he experienced with remembering people led those who knew him before dementia to see him as not being a full social person anymore. His daughter highlighted this for me when she explained that she has to remind herself that her dad's behavior occurs because his "brain is broken." The difficulty in continuing to engage in the same social networks where connections were created and maintained meant that Mr. Graham was slowly losing the recognition of full personhood according to those around him. Nevertheless, Mr. Graham continued doing activities that demonstrated his personhood such as attempting to talk to and connect with the men at his lunch table and his willingness to let me sit with him during our companionship visits.

Hospice and the Maintenance of Patients' Personhood

The processes of aging disease can alter the ability of someone to maintain their full personhood due to the changes that occur during the end-of-life period. However, hospice care is a form of care that people can choose which assists them with engaging in actions that help maintain full personhood. The goal of hospice is to provide comfort to the patient-family unit, and in doing this, hospice care helps to maintain personhood. The holistic combination of physical care and affective care results in personhood care for the hospice patient.

The Body and Patient Personhood

The retention of full personhood in hospice care is made possible by the care team's behavior towards the patients. When I asked hospice nurses at Heritage Care Hospice to explain what a day in their life might look like they often told stories of embodied care that involved deep personal connections and a commitment to maintaining the patient's preferences about their physical appearances. In our interview Mrs. Wells discussed doing things for her patients such as braiding their hair or applying makeup that they liked. Another nurse, Mrs. Jones also described snuggling with a patient and painting her fingernails. Both nurses were able to engage in these practices because they knew the personalities and preferences of each of their patients and they wanted to help these patients engage in behaviors that they enjoyed. While neither nurse spent much time describing the little things they did for their patients, the inclusion of these details is important. As hospice nurses they are not responsible for helping patients maintain their physical appearance, however they choose to engage in these acts of care because of hospice care's holistic nature. To care for a patient's whole being means that caretakers have to engage with their patients in an intimate way and form a relationship with them to fully understand their needs. Both nurses spent time engaging with their patients and discovering their preferences regarding their physical appearance so that they could care for the whole well-being of the patient. In doing this the nurses engaged in affective care that helped the patient continue to express their full personhood. In addition to this, by engaging with more than the physical body of the patient, the nurses provided their patients with a critical social connection that allowed them to maintain full personhood. Mrs. Wells and Mrs. Jones assisted their patients in using their bodies as mediums of expression when the patient was no longer able to physically do this by themselves.

The importance of the connection between the care provider and the patient is critical to the maintenance of full personhood. As sociologist Cindy Cain explains in her article about hospice professional's work identities, the hospice care system allows hospice professionals to have real emotions and make connections to the patients and their families (Cain, 2012). The space for connections and relationships that hospice creates contributes to the maintenance of the full personhood of patients as demonstrated by Mrs. Wells and Mrs. Jones.

Elana Buch exemplifies the importance of hospice care professionals in the maintenance of full personhood in her article about home care of elders in Chicago. Buch explains that home care nurses engage in embodied care. Embodied care refers to the way that the nurses participated in practices that were not expected. Buch describes nurses who would go through their patients' fridges and sniff milk to ensure that their patient did not consume anything that would make them sick. Doing this allowed the patients to retain their living preferences (Buch, 2013). In retaining their living preferences, the patients were able to engage in behaviors that allowed them to retain their personhood through the choices they made for their bodies. Instead of forcing patients to stop engaging in bodily behaviors, home care workers perform acts of care that allow the patient to maintain their lifestyle preferences, such as food consumption habits. In doing this work, the care giver provides the patient the ability to continue to use their body in some of the same ways they did before needing extra care. While the hospice nurses I talked to never described engaging in behaviors such as sniffing milk they did facilitate the patient's ability to make choices about their bodies and express full personhood through their physical appearance. By styling hair and painting fingernails the female patients were able to indicate that they were still engaging in embodied social behaviors that were expected of them before needing

hospice care. Through embodied, affective care, hospice care providers assist patients in using their bodies as a medium for personhood retention and expression.

Agency and Patient Personhood

Hospice provides personhood care by encouraging patient-family units to enact agency. In standard health care systems patients are also able to make decisions and enact agency, however it is often within the context of extending their life. When individuals decide they no longer want life-prolonging care, or when there is nothing left to do for a patient, standard biomedical care becomes less useful. The holistic care provided by hospice is driven by the patient's desires regarding their end of life and involves a deep commitment to listening to the patient's experience. Through this, patients have opportunities to enact agency even when their desires are counter to the goals of traditional biomedicine.

Kristina Jones, a Heritage Care Hospice nurse demonstrates this in her discussion of one of her patients. Ms. Jones explained that one of her former patients was experiencing back pain and was having trouble getting out of bed. Often the pain this patient was experiencing would be associated with aging and dying processes and treated with routine pain medications. Ms. Jones chose to take the time to do an assessment and listen to her patient's pain experience and identified an aneurysm that was in the process of rupturing. Ms. Jones and the rest of the patient's care team were able to treat the aneurysm and keep her comfortable. Ms. Jones created a space for her patient to enact agency in her care by listening to her experiences and valuing the body knowledge that the patient was presenting.

Hospice care's patient-focused care allows their patents the space to engage in autonomous choice about how they want to experience the end of their lives. Morgan Wells, a Heritage Care Hospice nurse, demonstrates this. When Mrs. Wells first begins visiting new

patients, she takes the time to sit with them and ask questions about their expectations and desires in the end of life. After meeting her patient and introducing herself Mrs. Wells runs through this series of questions. “How do you see the end of life? How do you picture it? …When I sit down with families and patients, I say like, what do you actually expect in your last several months of life? Like, do you want to be surrounded by family? Do you want to be awake and be able to, you know, have some sort of quality of life?” After having these conversations with her patients, Mrs. Wells tailors her care to their wishes and expectations. Enactments of agency require a person-based focus which hospice can offer. In Athena McLean’s article on dementia caregiving, she discusses the importance of health providers intentionally focusing their care on the patient instead of the disease. McLean exemplifies patient-focused care through practices that reduce disabilities like vision or hearing loss (McLean, 2007). Mrs. Wells’ questions are the foundation for patient-focused care. Mrs. Wells chooses to include the patient-family unit in the creation of their care plan and focuses that plan on their desires instead of the disease that is being faced.

By taking the time to engage in these conversations Mrs. Wells gives her patients the opportunity to make choices about their care. After receiving the patients’ care preferences Mrs. Wells can act to see the fulfillment of the patients’ desires. The patients are able to enact agency in their responses by expressing their desires and partnering with Mrs. Wells to create a care plan.

Social Networks and Patient Personhood

Central to personhood care is the space that is created within hospice care systems for the patient to be more than a body who is receiving physical care. In his chapter on hospice care’s ability to recover the art of dying, Farr Curlin discusses this space that hospice care creates. In

opposition to the technological and medicalized process of dying, hospice creates conditions for patients and their families to engage in the task of dying well (Curlin, 2015). As Curlin explains, hospice is an alternative pathway compared to a death that is riddled with medical intervention and care that largely focuses on the body and ignores the importance of affective care. Hospice creates a social space for the patient to be recognized as dying and take on the dying role (Curlin, 2015: 50). In standard medical care life extending measures are taken until there is "nothing left to do." When life-prolonging measures are being engaged in until the last minute there is not time for the patient to recognize that they are dying and take on a dying role, in which, the patient and their family members can prepare for their death. When a patient is recognized as dying there is an opportunity for them to be treated as more than a body that is not responding to life-prolonging care. Having a designated social role where a person is a dying individual who can continue to engage in social relationships contributes to the maintenance of personhood in the end of life.

The creation of space for an individual to be a dying person who retains their full personhood is demonstrated by the experiences of Mrs. Dean. As discussed earlier, Mrs. Dean has been able to retain much of her cognitive abilities unlike many of the residents that surround her. The low number of residents who have retained the same level of cognitive functioning as Mrs. Dean means that her relationships within the facility to not function like the relationships she formed outside of the living facility. Mrs. Dean has a close relationship with multiple of the women who work at her Creekside Assisted Living, however the demanding nature of their job means that they are unable to spend the quality time that Mrs. Dean needs and desires. In an interview with Mrs. Dean's sister, Susan Baker, she explained to me how Mrs. Dean entered hospice. The staff at the living facility noticed that Mrs. Dean was alone and was someone who

appreciated “real connection with people” which the staff simply couldn’t provide. The living facility helped enroll Mrs. Dean in hospice care with the hopes that it would ease her transition into death and provide her with companionship. After enrolling in hospice Mrs. Dean experienced a quick decline in which she moved in and out of a comatose state and often didn’t recognize people when she was awake. However, after beginning to receive hospice care, Mrs. Dean started to rebound and today is no longer in the active dying stage that she seemed to be in before. Mrs. Dean continues to qualify for hospice care today. In explaining the hospice care that Mrs. Dean receives, Mrs. Baker described the care team as being present with her and making her feel seen and heard. Mrs. Baker stated that hospice care allows Mrs. Dean to be “an individual that somebody recognizes, that [is] an individual, not just another sick person at hospice.” Mrs. Dean is made to feel visible and like a full person instead of just a body through what Mrs. Baker terms “nurturing care.” This nurturing care includes things such as assistance with showers and companionship visits. As Mclean explains in her article on the future of dementia care, care procedures can preserve the person and heal personal fragmentation. To maintain personhood an individual needs social acknowledgement and relations (Mclean, 2007: 199/204). The personalized, intentional, and affective care that Mrs. Dean receives allows her to engage in relationships with her caregivers in a way that provides meaningful connections that facilitate the maintenance of full personhood. The nature of the multi-person care team allows Mrs. Dean to interact with more people than she would if she were receiving a different form of care. The affective care that Mrs. Dean receives allows her to retain full personhood through caring relationships.

Hospice care is personhood care because it assists patient-family units with engaging in activities and practices that contribute the maintenance of full personhood. Hospice care is

medical care; however, it takes a de-medicalized approach by prioritizing the patient's preferences and experiences to craft a deeply personal experience of care and of dying. By de-centering technology, biological disease processes, and the physician, hospice care can provide personhood care to their patients. This personhood care can allow patients and their families to craft good deaths.

Hospice and the Maintenance of Family Caregivers' Personhood

Hospice care's main priority is the dying patient; however, the holistic nature of the care and the deep relationships that are formed create a space for the families to be cared for as well. The family caregiver of a person on hospice takes on a significant physical and emotional burden when they begin caring for their loved one. Often this caregiver is providing care long before hospice enters the picture. Many of the family members that I talked to discussed the years that they spent in the caregiver role before their loved one's condition got to be too much for them to handle without additional support. The family caregiver is tasked with making significant decisions for their loved one which may cause distress or dissent within the larger family group. The caregiver must also navigate how to be both a caregiver and a family member while making life-altering decisions. Sandra Miller's experience of taking care of her mother exemplifies the long expanse of time and difficulty that comes with being a family caregiver. At the time of our interview, Mrs. Miller had been providing care for her mother for 14 years and expressed the high level of burden and disruption to her life that this had caused. Mrs. Miller explained part of her burden of care came from her sibling's unwillingness to help care for their mother. Mrs. Miller referred to herself as an "only child" regarding caregiving due to her brother living in California and being "totally out of it." Mrs. Miller explained to me that often one child will take

on the responsibility of caregiving and the other will "count themselves out," leaving one child with the full burden of caregiving. Robert Rubinstein discusses this trend in his article on parental death. He explains that one child, often a daughter, experiences high degrees of burden and responsibility because they know more about their parents' health situations. Their increased knowledge means that they take on more caregiving responsibilities than their sibling(s) (Rubinstein, 1995). Mrs. Miller's experience with caregiving illustrates the trends between adult children caregivers and the degrees of burden that these caregivers face.

For many family caregivers this role is one of obligation. In her article on caring for aging parents in Peru, Jessaca Leinaweaver discusses the reciprocal obligation to care for parents. In Peru there is an expectation that children provide care for their parents to pay them back for the care that was provided to them as children (Leinaweaver, 2008). Similarly, Mrs. Miller explained her Bible-based reciprocal obligation to her mother. "People are thrown into this situation… you really are. And when there's nobody else but you, that's just what you do…the Bible says to take care of your family. So, there was no question about it for us." Mrs. Miller and her husband have been providing intensive care for her mother for the past 14 years during which time they have suspended many of their own desires and spent considerable time and money caring for Mrs. Miller's mother.

Elderly caregiving is an intensive job that can last for years depending upon the condition of the patient. While family caregivers are not at risk for losing the recognition of full personhood, they are still faced with changes to their ability to enact full personhood. The body, acts of agency, and social networks are critical not only to the achievement and maintenance of the patient's personhood, but to the family caregiver's personhood as well. Hospice care's

commitment to caring for the patient-family unit also means it provides personhood care for the family caregivers.

The Caregiver's Body and Personhood

The body is critical to the maintenance of full personhood for the family caregiver. In her ethnography of hospice care in the UK, Lawton exemplifies this in explaining that when a patient's body has deteriorated to the point where they need help engaging in basic activities such as walking or going to the bathroom, the caregiver's body becomes enmeshed with the patient's body. Lawton explains that this care leads to the body of the patient dictating both their own sense of self and the sense of self of the caregiver (Lawton, 2000: 106-107). When an individual loses the ability to express their personhood through their body, due to intense caregiving, they reduce their engagement in the critical connections that allow for full personhood to be met. This separation of the body from one's sense of full personhood contributes to the heavy burden that family caregivers experience daily.

The father and daughter dyad Mr. Graham and Mrs. Lambert demonstrate this concept well. Mr. Graham resides in an assisted living facility and suffers from dementia and other prior health issues. He has a strong aversion to the nursing staff at his living facility because he believes them to be unqualified and unfit to take care of him. His refusal to accept help from these nurses meant that Mrs. Lambert has had to assume increased responsibility for his caretaking. In our interview she described a breaking point that led to her enrolling her father in hospice. After moving her father into his assisted living facility, he would call her in the middle of the night and tell her he had an emergency that required her presence. Upon arrival, Mrs. Lambert would discover that the emergency was that he needed help changing his diaper or that he needed a shower. Mr. Graham's refusal to receive help from the staff at his living facility

meant that Mrs. Lambert was merging her body with her father's body through intense care such as toileting and showering, exactly the sorts of activities of daily living that the assisted living staff are supposed to support. When Mr. Graham was enrolled in hospice care, Mrs. Lambert was able to detach her body from her father's. Mr. Graham respected the hospice nurses because he believed them to be more qualified than the nurses at Mountain Top. He allowed them to help him with intimate body care such as showers and changing his diaper. Mrs. Lambert was able to re-enter her role as a daughter and re-engaged in practices that contribute the maintenance of her personhood.

The forms of physical care that hospice includes allows the family caregiver to create separation between their body and the body of the dying individual. The hospice care team steps in and assumes the caretaking role without the experience of a merged body. The merging of the family caregiver's and patient's bodies occur because of the deep familial relationship that is present before the caretaking begins. Hospice caregivers are intentional about forming relationships with their patients, and these relationships may even resemble familial relationships, however, there remains a difference in the nature of this relationship. Hospice caregivers can provide intimate care for the hospice patient's bodies without merging their own body because their relationship is based upon the expectation that they provide intimate caregiving acts. Hospice care prevents the merging of bodies in a way that allows family caregivers to maintain a separate personhood from that of their loved one.

Agency and Caregiver Personhood

The end of life and the processes that accompany it seem to limit both the patient and the family member's ability to engage in acts of agency. Dying has become a process that we try to control through medicalization and technology, however we are never truly successful in this

venture because at some point everyone dies. The inability of caregivers to stop or change the processes of dying make them feel as if they have no say in their loved one's end of life. While hospice cannot, and doesn't seek to stop death, it provides caregivers with opportunities to regain some of the agency that seems to be lost

In Mrs. Lambert's experience, the ability to choose hospice was a way for her to enact agency in the face of a distressing situation that was diminishing her ability to be a full person. Mrs. Lambert described the lack of agency that she had before enrolling her father in hospice care:

> So, in December my sister was here for Christmas…We had a long Zoom call with his primary care doctor. And he was just like, "You know, I think that hospice would be beneficial because they can provide some extra resources, extra help." He's [Mr. Graham] incontinent, like, all the possible ways incontinent. He would call me and say, "I have an emergency" and I would book it over there sometimes in the middle of the night, and it would be nothing more than "I need help changing and taking a shower."…I think what kind of hit the breaking point was that he was pooping himself and then he wouldn't change, and he would call me and then I would have to help him shower. No daughter should be doing this. My brother, one time when I was talking to him, he was like, "oh Jennifer, I understand." I said, "no, you don't. You don't understand until you're having to like wash poop off dad. You don't understand this. Like this is not okay." They have the pull strings all over the room. They have a bazillion ways to get someone, and they [Mountain Top staff] check on them too. They're very good there. They would come in, "Mr. Graham, are you okay?" "Yeah, I'm fine." He wouldn't tell them, and so he would make me come help him shower, help him change, help him get cleaned up. I was just crying. I was like, I can't keep doing this. I work full time. It's too much. So, our doctor had seen such a decline in his cognitive function that… it was just a good idea due to the dementia, and the additional services [to enroll in hospice].

Before enrolling her father in hospice Mrs. Lambert felt like she had very little control over her father's situation and her ability to meet his needs. As the only child available to care for him, she was being worn thin trying to provide for all his needs. The severity and short time span of his decline created a situation where Mrs. Lambert felt like she was unable to engage in acts of

agency. For family caregivers, choosing hospice is an act of agency that puts them in positions to enact future agency in their own lives and the lives of the people they care for.

In their explanation of care transitions, Martz and Morse discuss what they call a breakdown which leads to the institutionalization of a loved one. This breakdown occurs when the care gets to be too much, or the safety of the patient is at risk. The caregiver often experiences a physical breakdown due to the burden and strain of caring which contributes to the institutionalization of the family member (Martz and Morse, 2017). While this article is discussing the institutionalization of loved ones, we can apply this experience to enrollment in hospice as demonstrated by Mrs. Lambert's explanation of her breakdown with her father. The level of care she was required to provide became too overwhelming without help. Mrs. Lambert was able to seek help in the form of hospice care.

In Broom and Kirby's exploration of dying as a relational experience they explain hospice as something that can feel like a necessity rather than an individual or family decision (Broom and Kirby, 2012). Their assertion highlights the way that dying can limit people's ability to engage in acts of agency, however I would argue that choosing hospice can be thought of as an act of agency in the face of death. Nothing will stop death forever, but through hospice, the family caregiver is able to bring their inner desires and thoughts forward to create a care plan that produces results in the world which makes the dying process feel more manageable. Mrs. Lambert was able to take an active role in her father's care and engage in an act of agency by choosing hospice which allowed her to continue enacting full personhood.

Social Networks and Caregiver Personhood

Being integrated into social networks is critical for the achievement and maintenance of personhood. As we saw demonstrated by hospice patients, the loss of one's social network due to

aging and disease can lead to a loss of personhood. Family caregivers are equally as likely to lose their social networks when their family member requires intensive care. In discussing the social interactions of end-of-life care, Daniel Briggs explains the tendency of caregivers to give up their jobs and reduce their social lives to maintain the support and care that their family members need (Briggs, 2010: 45). Mrs. Miller detailed the loss of social life that she has experienced while caring for her mother. Mrs. Miller's mother has severe dementia, is blind, and is going deaf. Mrs. Miller's mother needed to be in a memory care facility, however Mrs. Miller had not found a memory care facility that she was comfortable placing her mother in. Mrs. Miller decided to have her mother live in a skilled nursing facility instead of a memory care facility so that she had more peace of mind about the quality of care. However, while Mrs. Miller believes that the skilled nursing facility gives quality care, they are not able to care for her mother in the intensive way that is necessary. This means that Mrs. Miller assumes more of the care-taking role than would be necessary if her mother were in a memory care facility. Mrs. Miller explained that she hasn't taken an overnight trip in the past year because she must be available for her mother at any time. When asked about how her mother's dementia has impacted her life, Mrs. Miller stated that she wished she had begun to do things on her bucket list before retirement because now that her mother needs care she cannot do these things. Mrs. Miller's social network and social interaction has been limited to the people that can come visit her, or the people who are within a round-trip day's drive. While Mrs. Miller expressed gratefulness for her ability to care for her mother, she frequently re-iterated the limitations that this placed on her. Mrs. Miller's sociality was bounded by her mom's diminished abilities and increased needs each day.

Hospice care cannot guarantee that the family caregiver will be able to maintain all social networks or engage in these networks in the same way, but it does allow the caregivers the ability

to engage in their social networks more than they would be able to without this care. As discussed previously, meaningful social interactions that keep the individual in a social network must occur for a person to retain full personhood. Mrs. Wells demonstrates hospice care's ability to keep family members in a social network. When Mrs. Wells first began seeing her patient, he was at the beginning stages of his dying process and didn't require much from her. This made him reluctant to accept her help and allow her to enter his house. Mrs. Wells described his wife as a socialite who didn't know how to handle her husband being sick. The patient's wife wanted to continue engaging in her social world the same way she had before her husband entered hospice care, but she simply couldn't. As Mrs. Wells continued to visit this couple, they slowly opened up to her. Eventually the couple would get donuts and coffee to share with Mrs. Wells when she came by. The three of them would spend over an hour just talking and connecting. As the patient's condition worsened and he got closer to death, they continued to engage in their donut and coffee tradition until the patient passed away. Mrs. Wells' decision to engage in affective care through sharing a meal and talking with her patient allowed the socialite wife to continue to engage in the social interactions she was missing due to her husband's condition. While the wife's social life was dramatically altered, she was still able to engage in forms of sociality that she valued and retain full personhood through Mrs. Wells. The nature of hospice care's interdisciplinary care team means that there are always multiple team members visiting the patient-family unit throughout the week. This influx of individuals entering the patent-family unit's home increases the opportunities for sociality and forming connections. As Mrs. Wells' story demonstrates, through the hospice caregivers the patient-family units can engage in meaningful connections even when there is a decreased ability to be fully a part of the social world.

Much like hospice patients, family caregivers will experience diminished personhood due to the intensity of end-of-life care. However, the family caregivers will continue living after their family member's death which makes it crucial that they maintain their full personhood throughout the caregiving process. Hospice cannot and will not eliminate all the changes that a caregiver experiences, but it does provide personhood care which helps them to cope with the loss of a loved one and continue to live afterwards.

Hospice Care as Whole Person Care

Hospice care is a deeply personal and personalized form of care that goes beyond standard biomedical care. Death outside of hospice care, especially for elders, often occurs in a sterile hospital room which limits the way that the patient can interact with their world and loved ones. The rules and regulations of hospitals force family members to abide by visitation hours and maximum capacities. Hospital-based care, while extremely important, prioritizes efficiency and profit over the experiences of the patient and their families. Hospice care does not require patients and their family members to enter unfamiliar spaces to receive care. They meet the patient where they are both physically and mentally. The affective care engaged in by the Heritage Care Hospice nurses illustrates the way that hospice care seeks to prioritize the patient's experiences. Hospice care is personhood care because it prioritizes the patient-family units' connections that allow them to be recognized as full persons

Through providing holistic person-centered care, the retention of personhood gives hospice professionals the ability to engage in healing. Hospice as healing does not always mean a restoration of physical health, but can refer to the restoration of spiritual, mental, or emotional health which can contribute to the creation of good deaths. Dying is an experience that is often

overwhelming and is always inescapable, however, through hospice care it becomes something that is manageable for both patients and their families.

Chapter 4 Emotional, Physical, and Relational Healing for a Good Death

Shirley Carter has been receiving hospice care from Heritage Care Hospice for over a year due to congestive heart failure but firmly believes that she is not in hospice care to die. Mrs. Carter instead believes that she is using hospice care's services to heal her body. While talking to Mrs. Carter about her experience she boldly explained "I have not thought for one minute that I'm in hospice to die." While Mrs. Carter's experience with hospice has involved physical healing, the purpose of hospice care is not to provide physical healing, curative treatments, or life-prolonging care. Hospice care is meant to provide comfort and support to dying patients and their family members. The goal of hospice is to walk people through the dying process by educating them and providing physical and mental support. Hospice care is holistic care that is centered around relationships which allow care givers to provide person-centered care. Through the care given in hospice organizations, patients and their families receive affective care that helps them retain full personhood and creates opportunities for physical, emotional, spiritual and relational healing.

To begin thinking about hospice care as a vehicle for healing we must expand our understanding of what healing means and how death is experienced differently across forms of care. In the context of hospice care, healing can refer to the physical body recovering from its ailments, or it can refer to the improvement or mending of emotional, spiritual, and relational health of a patient. Standard biomedical care (like hospitals) and hospice care are both meant to provide for the needs of the patient. While hospital caregivers do their best to meet the needs of the patient, the system is not designed to provide the same kind of death that is possible in hospice care. Mrs. Jones, a hospice nurse for Heritage Care Hospice, previously worked in an ICU unit at a hospital and experienced many patient deaths while employed there. While not

every death aligns with Mrs. Jones' description, her experience in the ICU provides a generalized idea of what it is like to die in an American hospital. Ms. Jones described hospital death experiences as "being told what to do" where patients have little to no say over the care they receive. She would often hear patients crying out in their last few hours asking for help, to which nurses would respond with medication for restlessness and anxiety. Doctors would often avoid talking about death or giving prognoses that indicated that death would occur soon because they did not want to have difficult conversations with their dying patients. Death in the hospital setting seems to be characterized by strife and pain. Comparatively, Ms. Jones described deaths in hospice care as "providing alignment… it's peaceful, like, fall asleep smiling, and then pass away. So, the difference [between hospitals and hospice care] is, it's huge." While not all patients' experience in hospice care will end with them smiling and slowly drifting off, hospice creates a different experience at the end of life than the hospital environment can create due to its structure. Ms. Jones explained that the families of hospice patients can attempt to live normal lives without the constraint that hospital visiting hours would create. In hospice care, patients can relax in the comfort of their own homes surrounded by their personal possessions and family members. Patients in hospitals are surrounded by unfamiliar people and medical technology which can be overwhelming or disorienting to patients. While some individuals are satisfied with the kinds of deaths that the hospital structure can provide, others desire a more intimate and personalized form of end-of-life care. As another Heritage Care Hospice nurse stated, hospice involves "beauty in death and peace of outgoing." Death through hospice is a space where dying is acknowledged, and care is specialized. In doing this, hospice is alternative health care where the person, not a cure or disease, is the center of attention.

Hospice organizations have evolved to provide care for more than just the patient's body. Caring for the patient's whole self has become central to the goal of hospice care. The whole self refers to the mind, body, and social connections that make a person. Additionally, caring for the family members of the patient has become a critical aspect of providing holistic person-centered care. A patient rarely experiences the end of life in isolation. The social nature of life and death means that the family unit must be included in the care that is provided through hospice. The end-of-life period and the approach to care that hospice caregivers use creates opportunities for whole body healing to occur. Hospice is not only affective care that helps individuals retain full personhood, but it is healing care for the patient-family unit.

Physical Healing and Recovery Through Hospice

While the intention of hospice care is to help people through the dying process, there are instances when hospice produces physical recovery. Sometimes, hospice services are provided to individuals who do not continue to meet the eligibility requirements of the Medicare hospice benefit. When a patient no longer qualifies for hospice due to healing, they undergo a "live discharge." A live discharge occurs when a hospice patient no longer shows a continual decline in health and a movement towards beginning an active death period. The hospice organization will therefore deem that the patient no longer needs their services and will remove the person from their care.

The most perplexing live discharges occur when patients seem to miraculously get better. The Medicare Payment Advisory Commission describes this occurrence as the "hospice effect" where patients "experience improved health in hospice…to the point that clinicians no longer estimate a life expectancy of six months or less" (Medicare Payment Advisory Commission). In

special cases, hospice care seems to provide physical healing and recovery for patients even when these services are not intending to provide rehabilitative care. This occurs because hospice's approach to care can create an optimal healing environment that is based on reciprocal relationships where the patient and caregivers are willing to share intimate parts of their lives with one another. The creation of an optimal healing environment allows hospice patients to physically heal. Not every patient that experiences healing and improvement through hospice care will qualify for a live discharge, however the stories of physical healing and bodily improvement are important to understanding hospice care as an alternative form of medicine. The experience of physical healing through hospice care and its complexities can be evaluated through the stories of Margret Dean and Shirley Carter. Both women have been receiving hospice care through Heritage Care Hospice for over a year. While the women's stories are very different, they were both enrolled in hospice during what seemed to be an active dying period, but have since experienced a re-bound that reversed the effects of the active dying period,

As discussed in chapter 1, Margret Dean entered an assisted living facility five years ago after undergoing knee surgery. She struggled to recover and eventually experienced a fall which placed her in a skilled nursing facility. After healing from both the surgery and the fall, Mrs. Dean moved into her assisted living facility, Creekside Assisted Living, to ensure that she would get the help that she required. Mrs. Dean lived at Creekside for three years before receiving hospice care, during which, she slowly experienced a whole-body decline. Mrs. Dean's sister, Susan Baker, explained to me that Mrs. Dean's health started to be "down" more than it was "up." Mrs. Dean stopped attending meals in the dining room, wouldn't get out of bed, and was having trouble breathing. The staff at Creekside noticed this sharp decline and helped to enroll Mrs. Dean in Heritage Care Hospice where she began to decline further. At the time of this sharp

decline Mrs. Baker was planning on traveling to Guatemala with her family. The staff at Creekside informed her that Mrs. Dean would probably not live through the duration of Mrs. Baker's trip. At the time, Mrs. Dean was unconscious for most of the day, and when she was conscious, she didn't seem to remember the people around her or understand what was going on. Believing that she could not do anything else for Mrs. Dean, Mrs. Baker made the difficult decision to go to Guatemala not expecting to see her sister again. During the week that Mrs. Baker was out of the country Mrs. Dean began to slowly rebound. Mrs. Baker explained that when she went to visit Mrs. Dean in the weeks after her trip "she'd be awake, and then she'd be sitting up, and then she'd want to be in the wheelchair." Today Mrs. Dean wheels herself around Creekside, stops to talk to everyone she knows, and is adamant that she's not dying. Mrs. Baker explained that Mrs. Dean still experiences periods of decline, after which she is never as healthy as she was before that decline. Even with these periods of decline, Mrs. Dean has not re-entered the active dying period. Mrs. Dean's rebound is largely unexplained and a bit miraculous, however the care that Heritage Care Hospice provided for her has undoubtably contributed to her physical recovery.

While Mrs. Dean's story of recovery seems to be miraculous, Shirley Carter's story of recovery highlights key differences between health care systems that prioritize life-prolonging care and systems that prioritize comfort and patient choice. Mrs. Carter, who recently turned 90 years old, has an extensive history in health-adjacent fields. She began her professional career as a special education teacher. After divorcing her husband, she accepted a teaching job in the children and adolescent's unit at the state mental hospital and was eventually transferred to Norman Public Schools as a psychologist, during which time, she finished both her MA and PhD in psychology. Mrs. Carter eventually started teaching classes at OU, OCU, and Nova University.

Mrs. Carter described herself as a "learn-acholic" and a very social person. Before entering hospice care, Mrs. Carter had a stroke which led to congestive heart failure. Mrs. Carter was able to regain the ability to walk and speak with three years of in-home health care. After recovering from her stroke Mrs. Carter caught COVID-19 which exacerbated symptoms from her stoke and placed her in the hospital in a nearly unconscious state for two months. While at the hospital, Mrs. Carter's care team attempted to restore her health, but eventually decided there was nothing more they could do for her. Having declared this, Mrs. Carter was enrolled in hospice care and moved back to her residence with the intention to make her comfortable through the process of dying. However, after being moved home, Mrs. Carter's new care team stopped giving her the medications that the hospital was providing, and Mrs. Carter was able to regain consciousness. After regaining consciousness, she realized the hospital staff had been over-medicating her with drugs that she knew she was unable to take. With her consciousness back, Mrs. Carter was able to engage with her hospice care team and explain which medications she could and couldn't take, which facilitated her ability to move out of the active dying period.

Additionally, while at the hospital, Mrs. Carter had developed a pressure sore on her foot the size of a silver dollar. This wound kept Mrs. Carter from being able to stand and take care of her own bodily needs. Hospice care has provided wound care and shrunk the wound to the size of a penny. While talking with Mrs. Carter about her experiences in both the hospital and hospice care, she explained that her goal was to completely heal the pressure wound and be discharged from hospice. Mrs. Carter was adamant about not wanting to return to the hospital for fear that "they might kill [her]." Today Mrs. Carter is still bed bound but plays an active role in her health care. She engages in exercises to strengthen her muscles, purchases products such as compression sleeves to help with swelling in her legs, and engages in research on alternative

therapies, such as light therapy, to help facilitate her healing. As stated earlier, Mrs. Carter expressed that she had "not thought for one minute that I'm in hospice to die." Mrs. Carter understands that hospice care is intended to provide care services for dying individuals, however due to her experience of recovery she no longer believes she is close to death and instead thinks about hospice care as a tool she can use to continue recovering.

Both Mrs. Dean and Mrs. Carter's physical recovery stories are atypical of most hospice patients' experiences, however they highlight key aspects of why hospice care can be understood as a vehicle for healing. Hospice organizations and professionals are intentional about the environment that they create. Sakallaris et al. describe an optimal healing environment as a "healthcare system that is designed to stimulate and support the inherent healing capacity of patients, families, and their care providers" (Sakallaris et al, 2015). While hospice care is not focused on physically healing individuals, they are designed to support both the patient and family members physically, mentally, socially, and spiritually during the end-of-life period. This supportive intent creates an environment in which patients are not told "there's nothing else we can do for you." In her exploration of end-of-life care as an optimal healing environment, Susan Silver explains that the pre-ordained outcome of death in hospice care means that the care team will not stop providing care, as a hospital care team would, because they believe they cannot do anything else (Silver, 2004). Comfort care does not stop until the patient dies, and bereavement care for families continues for a year after the patient's death. When Mrs. Carter and Mrs. Dean seemed to be at death's doorstep their hospice care team continued to do everything they could to make them comfortable.

An optimal healing environment must have people in relationships where they're collaborating to create both healthy behaviors and a healthy environment (Sakallaris, 2025). Mrs.

Carter's experience demonstrates collaborative relationships that work toward cultivating health. After she had regained consciousness, Mrs. Carter was able to explain her needs regarding medication to her care team and was able to express her desire to heal her pressure wound and walk again. The nurses she has worked with have facilitated her healing by being in relationship with her, working towards her goals, and assisting her in incorporating alternative healing therapies. While the hospice nurses' intentions are not to create an optimal healing environment, their commitment to patient-centered care results in practices that produce an optimal healing environment. Sakallaris and colleagues explain that healing can occur without a cure (Sakallaris et al, 2015: 40). While Mrs. Carter and Mrs. Dean have not been cured of all their health issues, they have experienced unintended physical healing. Their initial rebounds out of the active dying period, and the healing that has occurred during their enrollment in hospice highlights the whole person healing capacities of hospice care.

An important aspect of the optimal healing environment that is created through hospice care is the relationships that are formed through these services. In discussing her experience with hospice care, Mrs. Carter described her relationship with her nurse as a reciprocal relationship. She described the deep connection that they had and the dual intimacy that they shared. Mrs. Carter's nurse helped her with intimate parts of living such as showers, toileting, and changing clothes. In turn, her nurse also shared her intimate and personal desire to go back to school and get a college degree. Mrs. Carter encouraged her nurse to enroll in a local community college. After enrolling and starting classes, Mrs. Carter's nurse would share her experiences from class and the things she struggled with, such as writing papers. Having been a college professor herself, Mrs. Carter advised her nurse on how to best approach her work and encouraged her when the nurse believed she could not make it through. Mrs. Carter and her nurse exemplify a

reciprocal relationship that is critical to hospice care and the formation of an optimal healing environment.

Irene Estores and Joyce Frye, two holistic medicine researchers, explain integrative medicine as medicine that reaffirms the importance of the relationship between the patient and the professional caregiver, focuses on the person as a whole, and makes use of alternative therapies (Estores and Frye, 2015: 369). Integrative medicine is a way to prioritize the patient over the disease in health care. While hospice care doesn't explicitly practice integrative medicine, many of the values found in this concept align with the values of care on which hospice is based. Mrs. Carter was able to engage in alternative light therapies through the help of her hospice nurse who brought her to the light therapy and encouraged her to seek out the care that she believed would help her. In assisting Mrs. Carter with finding and receiving alternative care, her nurse was prioritizing Mrs. Carter as a whole person instead of seeing her as only a body to treat. Furthermore, her commitment to helping Mrs. Carter get this kind of care demonstrates the deep relationship between Mrs. Carter and her nurse. Deep, intentional relationships are critical to optimal healing environments and to providing quality hospice care.

Mrs. Dean has also been able to experience intentional relationships that contribute to her overall well-being. While I do not claim to be the reason Mrs. Dean has experienced healing, I do believe that our relationship has contributed to Mrs. Dean's overall well-being. My visits with Mrs. Dean started in February of 2024 and initially were not very long and stayed surface level. I began by reading to her for 30 minutes every two weeks, however I started to realize how much we both enjoyed these visits and started going to visit her every week for an hour or more. During these visits we would talk, share pictures, and eventually get around to reading our books. I would talk to her about the things I was struggling with in school, and she would

encourage me and tell me about the things she did that week. For Mrs. Dean, our time together provided her with critical social interaction that was largely lacking at Creekside. The high number of patients with dementia or other cognitive illnesses meant that Mrs. Dean had few people around her to interact with. By visiting each week, Mrs. Dean was able to engage in meaningful conversation which helped her to feel like a normal adult, while I found fulfillment and encouragement in our friendship.

In a study on the importance of relationships in palliative care, Mok and Chui found that a relationship to one's nurse provided an incentive to live, helped patients find security, and helped to ease emotional suffering (Mok and Chui, 2004: 480). While Mok and Chui were studying palliative care we can extend their findings to hospice care with the knowledge that hospice care is a specialized form of palliative care. Similarly, Raudonis, a nursing professor, found that having an empathetic relationship, where the patient was acknowledged as an individual with value, improved and maintained the physical and emotional healing of hospice patients (Raudonis, 1993: 304). Mrs. Carter and Mrs. Dean were able to cultivate deep relationships with their hospice care team providers. These relationships affirm that they are valuable and deserve care. Through these relationships trust was formed, and the optimal healing environment was cultivated through intentional patient-centered care.

While the experiences of rebounding from an active dying period are unusual, Mrs. Carter and Mrs. Dean's stories show the importance of the environment that hospice can create, and the potential for healing to occur within these spaces. While the chances of experiencing physical healing are low, patients and family members can experience some form of emotional or spiritual healing through hospice care. The ability to experience these kinds of healings are

possible because of the space that hospice care creates for the dying patient to be actively dying but still be a full person.

Hospice as a Space for the Dying Individual

In mainstream health care systems dying individuals are seen as failures of medical practice. Success in life-prolonging medicine is based on the ability of medicine and medical practices to cure people and keep them from dying. Instead of embracing the fact that everyone will die eventually, standard biomedical systems seek to prolong patients' lives as long as possible. This creates a space where individuals who cannot be cured or saved from death become marginalized and are seen as less than fully human. standard health care systems create a paradox where old people are unable to be categorized as dying persons, while simultaneously being categorized as dying and made into an "other". In Chapple's chapter on the disappearance of dying she explains that when a person is labeled as being at the end-of-life it stigmatizes them as an "other" who doesn't belong in "mainstream society" (Chapple, 2018: 433). Mainstream society is reserved for the living who can contribute to the creation of a constantly evolving society. Simultaneously, standard health care systems are resistant to labeling old people as dying persons. Anthropologist Sharon Kaufman explains the "gray zone" between life and death in regard to "old age, disease, and natural death" (Kaufman, 2005: 78) Medicine has struggled to separate normal effects of aging from disease processes. Kaufman explains that if "old age is viewed primarily as effects of the disease processes on the body, then the person-in-the-patient tends to be effaced" (Kaufman, 2005: 78-79). This results in old people not being seen as or being allowed to be dying persons. The desire of biomedicine to understand and eliminate death through biology means that dying people become "others" who cannot be fixed by medicine and

therefore cannot fit into society like everyone else. The desire to heal and stave off death also prevents medicine from acknowledging individuals who are dying. This paradox creates a space where the full personhood of dying individuals is questioned. As discussed previously, hospice care is personhood care in that it helps to maintain the full personhood of both patients and their family members through the process of dying. Hospice care is also a space where healing can occur. This is made possible by acknowledging patients as dying individuals while still recognizing their full personhood and value as a human.

While it is known that hospice is a holistic form of care that seeks to treat the whole person, what is less known is the way that this occurs. Hospice treats the whole person through creating a space where they are not a dying body, but instead, are a person who deserves care. In chapter three I discussed the importance of a social space in relation to the ability to provide personhood care. Curlin explains that hospice care creates a "recognizable social space" where the patient is "described as dying" and takes on "the dying role." In acknowledging that a person is dying and allowing them to take on the social role of a dying person, hospice care providers are able to focus on helping the patient and family members create desirable deaths (Curlin, 2015: 50). This is exemplified by Mrs. Miller and her mother. Mrs. Miller's mother is 100 years old and suffers from dementia and the effects of being old. While Mrs. Miller's mother is not in an active dying period she is still labeled as a dying person due to her ailments. Having the label of a dying person allows Mrs. Miller and her mother to receive the help that they need, and work towards creating an environment that will help her mother to pass peacefully. Being labeled a dying individual creates a status that opens opportunities for care that are not available otherwise. For instance, having a 6-month prognosis makes someone eligible for hospice care under the Medicare hospice benefit. Without this label, dying individuals are unable to access the

care that they need or want. In hospice, Mrs. Miller's mother is still acknowledged as a person while simultaneously being understood as someone approaching death. The socially recognized space for the dying that is created by hospice care allows both Mrs. Miller and her mother to focus on preparing for death.

Being recognized as an individual instead of a sick person has greatly helped Mrs. Dean heal both physically and emotionally. When talking to Mrs. Baker, Mrs. Dean's sister, she explained hospice as care that is "present with [patients] so that they're not just another dying person. That they have had a life, and they continue to have a life, and that they matter. You know, they're somebody that's not just being taken care of by staff somewhere." When asked to describe her understanding of Mrs. Dean's experience with hospice care she stated "well, just that she feels more loved, and more, you know, like she knows that she's a person." An important part of creating a space for people to be acknowledged as a dying person with value is the formation of empathic relationships. As discussed earlier, Raudonis highlights the importance of acknowledging people as individuals with value when creating empathic relationships (Raudonis, 1993). For Mrs. Dean, hospice care affirms her value by providing her personal care such as showers and companionship visits. Mrs. Dean can simultaneously be a dying person and a person with value through the relational care that she receives in hospice.

Being acknowledged as a dying person with value requires a comfort with discourse on death and dying. Death talk is discourse that involves the end of life, dying, and the care that people receive during their end-of-life period. Hospice care cultivates a space for healthy death talk to be engaged in which facilitates comfort with death that is necessary for people to be both dying and valuable.

The comfort with death talk was demonstrated to me while doing a hospice companionship visit over the summer of 2024. During the summer months I began to plan my visits with Mr. Graham during his facility's lunch time to allow me to talk to multiple people at the facility. One day when I arrived at Mr. Graham's assisted living facility, Mountain Top, I met him at his door for lunch time. As soon as Mr. Graham walked out of his door, I asked how he was doing to which he replied, "my friend down there is dying." I was immediately shocked and unsure if he would be upset by this occurrence. I replied that I was sorry, to which he looked at me with a blank face and replied, "this is a place they send you to die" and started walking towards the dining room. That day at lunch only Mr. Graham and his table mate Edward Isaiah were present. Both men insisted I sit in one of the chairs already placed at the table instead of pulling up a chair like I normally did. I later discovered that the chair they insisted I sit in belonged to the friend of Mr. Graham who was dying. Mr. Isaiah mentioned the man, Mr. Johnston, and stated that he didn't think he would make it through the night. Mr. Graham looked to me and stated, "the cancer lit him up inside" which redirected Mr. Isaiah and Mr. Graham's conversation; however, Mr. Graham later turned to me again and stated that "this was a place they sent you to die." As I continued to visit during lunchtime, I found that Mr. Graham and Mr. Isaiah would discuss other residents' health statuses while pointing at people and not lowing their voices. It seemed to me that no one was bothered by their conversations about other peoples' health statuses which occurred rather frequently. Mr. Graham and Mr. Isaiah often engaged in death talk because they were surrounded by an environment where it was normalized to be a dying person while also being a person with value. Their conversations about peoples' health and Mr. Johnston's impending death reaffirmed their positions as dying persons with value.

Furthermore, in a study on experiences with palliative care, Pollack and colleagues found that patients often struggled with not knowing what death was going to be like and anticipated it would be unpleasant and stressful (Pollack et al., 2024). Hospice creates a space where it is normal and expected to engage in death talk and acknowledge people as dying individuals. In doing this, death becomes less fear inducing and people can engage with dying individuals and learn from their experiences, as Mr. Graham and Mr. Isaiah were able to do through their tablemates' death.

For family members, death is something that is infrequently experienced and characterized by fear because they do not understand the process of dying. In her exploration of death and the corpse Elizabeth Emerick explains that the unknown of death creates fear. Additionally, the repulsiveness of the processes after death encourages us to remove the end of life and decomposition process from everyday life (Emerick, 2008). While hospice doesn't address the decomposition process, it is intentional in walking families through the process of dying and explaining what each stage may look like. Education is critical to hospice care and creates a space where death talk can be engaged in a productive way.

The space to engage in death talk and acknowledge patients as dying individuals with value contributes to the optimal healing environment. When dying patients have an acknowledged status or label, they can engage with those around them in meaningful ways. Mr. Graham and Mr. Isaiah demonstrate this well. They were comfortable with the fact that they were getting closer to death and had social positions that affirmed their continued personhood. Through this they were able to openly engage in death talk. An acceptance of their social position and comfort with death talk opened the opportunity for healing. While neither man described instances of healing to me, they displayed a comfort with death that is critical to the

emotional, spiritual, and relational healing that can occur through hospice care. The optimal healing environment is often focused on physical healing, however much of hospice care's healing is emotional and spiritual. Hospice care helps heal the wounds that are created in the processes of the end of life by taking care of the patient-family unit as whole people.

Healing the Patient-Family Unit

Contemporary health care systems have created the narrative that healing means being cured and escaping the clutches of death and disease, but as Sakallaris and colleagues addressed, healing can occur without a cure (Sakallaris et al., 2015). Healing through hospice care does not mean escaping death but instead is about mending the personal fragmentation that is created by the end-of-life processes. Personal fragmentation is a deterioration of parts of an individual's whole well-being. This healing occurs by providing whole person care for the patient-family unit. In McLean's chapter on recommendations for dementia caregiving, she explains that care is a negotiation between the caregiver and care receiver. When care is provided in a person-centered way and seeks to address the patients' disabilities, the personhood of the patient is preserved and there is an opportunity to heal personal fragmentation (McLean, 2007). Hospice care provides person-centered care by having a care team that can meet not only physical, but emotional, spiritual, relational, and legal needs. In the effort to make people comfortable with death, hospice care seeks to provide resources, education, and help in managing disabilities as the effects of the end-of-life progress. As discussed earlier, hospice care opens opportunities for healing by acknowledging death. Chapple explains that this acknowledgment of death creates an opportunity for spiritual connection, restoring relationships, and saying goodbye (Chapple,

2018). Each of these opportunities contributes to healing the personal fragmentation that death creates.

The opportunities for healing care through hospice are inherently social. The family members of the dying individual are important to the healing of the patient. Simultaneously, the family members are also in need of healing from the end-of-life process. In talking with Heritage Care Hospice nurses, they often expressed to me the importance of the families in the work that they do. When asked how she would explain hospice to someone who had minimal knowledge about it, Gina Rodgers explained that hospice is intended to help people transition to death, but that they "treat the whole family, of course, when we're in the homes." She explained that "sometimes the family is more in need than the patient as far as emotionally, they're just not knowledgeable about everything going on." Mrs. Rodgers explained how she would educate family members and help walk them through the difficult emotions that accompany death. Mrs. Rodgers' explanation of hospice services highlights the importance of families to hospice care.

In her ethnography of assisted dying in Oregon, Anita Hannig explains the idea of relational suffering. Relational suffering refers to the notion that suffering is not confined to one person but is mediated by relationships with other people (Hannig, 2023: 164). Hannig details the experience of the sisters Beatrice and Ruby. Beatrice nursed Ruby as her health deteriorated and helped her navigate the bureaucracy of obtaining the lethal medication required for aid in dying. In the end, Ruby died without being able to make use of the lethal medication (Hannig, 2023). While Beatrice was not the one actively dying, she experienced much of Ruby's suffering by helping her navigate the end-of-life period. While Hannig is discussing experiences with aid in dying, relational suffering can be seen in any end-of-life care system as the family members assist the patient in navigating the end-of-life period. The family members that Mrs. Rodgers

described often experience relational suffering due to the intense caregiving needed even with the involvement of hospice care.

Often the family members of patients have little, if any experience with the end of life and can become overwhelmed with the responsibilities and expectations of caring for a dying loved one. The difficulty of intensely caring for a loved one and the personal fragmentation that can be produced from the care is demonstrated through the story of Mr. Graham and his daughter Mrs. Lambert. As discussed in chapter three, Mr. Graham resides in Mountain Top Assisted Living Facility and suffers from dementia and other health ailments. His resistance to accepting help from Mountain Top nursing staff meant that Mrs. Lambert was providing intensive and deeply personal care for her father such as giving him showers, cleaning up after incontinence issues, and scrubbing his room to ensure it was clean. When Mr. Graham was enrolled in hospice, Mrs. Lambert was able to step back into her role as a daughter and out of the intensive caregiving role. Not only did this enable her to regain lost aspects of her personhood but it also allowed her to heal her relationship with her father. Instead of feeling an obligation and resentment towards the care she was providing she was now able to engage with her father in a way that aligned more with the role of a daughter.

In her article on the experience of children caring for their parents, Conway explains that when people are required to combine the caregiving needs of their family members with their own personal needs, they experience a role overload. The caregiver is not able to meet all the needs of their dying loved one, their own needs, and the needs of any other dependents that they may have. This role overload can contribute to family strain and personal health deterioration (Conway, 2019). Family strain and personal health deterioration are a few examples of personal fragmentation that can occur when providing care for a dying individual. Mrs. Lambert described

a role overload when she explained that she was having to care for her father in a way that no daughter should have to do. The necessity of toileting and showering Mr. Graham created personal fragmentation and role overload that led to a breakdown resulting in Mr. Graham being enrolled in hospice care. Hospice care allows family members, like Mrs. Lambert to step away from the intensive caregiving role and heal their personal fragmentation.

Hospice care professionals contribute to the healing of personal fragmentation in families through the deep relationships that are formed. Mrs. Carter shared her deep connection to her hospice nurses and explained the relationships as reciprocal relationships. In our discussion she also talked about the relationships the nurses had formed with her children. Mrs. Carter's son developed schizophrenia when he was a teenager and currently resides with her. Her son waits in the living room each day for a bus that brings him to a program for special needs adults. Mrs. Carter explained that her son does not initiate conversation, but her nurses continue to greet him and wish him a good day. Mrs. Carter stated that "it's nice to know that the people taking care of you have relationships with your family as well. It's not just with you." Mrs. Carter valued the relationships with her care team not only because of the services she received, but because they were intentional with extending care to her family as well. Mok and Chui explains that oftentimes hospice nurses form such deep friendships that they become part of the family (Mok and Chui, 2004). While Mrs. Carter did not refer to her nurses as part of her family, she did continually express how important her nurses were to her and the value they had to her entire family. The deep relationships that are formed between nurses and patients are extended to the families to help them understand and accept the processes that are occurring to their dying loved one.

Emotional and Spiritual Healing

Healing within hospice care can be experienced on an emotional, spiritual, and relational level. In talking about her experiences with hospice care, Mrs. Baker described hospice professionals as personal advocates for their patients. Mrs. Jones, a Heritage Care Hospice nurse, exemplified Mrs. Baker's perceptions of hospice nurses as advocates. While discussing the importance of having the whole body aligned at the end of life, she shared the story of one of her patients who was experiencing severe stomach pain, nausea, and vomiting. Mrs. Jones tried to identify a medical reason for the pain and treat the symptoms with medication, but nothing worked. Mrs. Jones took time to sit with her patient, during which time, the patient shared that she had experienced a miscarriage 50 years ago. After this miscarriage the doctor took the baby away and refused to let the woman see her baby to say goodbye. She was unable to bury the body and properly grieve the loss. Mrs. Jones recognized her experience as unresolved grief and quickly called the Heritage Care Hospice chaplain. The chaplain was able to talk through the experience with the woman and help her forgive herself for the situation. After talking with the chaplain, the patient passed away 30 minutes later. Mrs. Jones chose to sit and listen to the complexities of the issues that the patient was dealing with. Hospice professionals can act as advocates for their patients and contribute to healing due to the "slowed down care" that they practice. The idea of slowed down care was established by Lerer in her study of hospice care. Lerer explained slowed down care as the choice of care providers to engage in their patients' lives outside of their diseases. Slowed down care attempts to understand the full complexities of a patient's problems (Lerer, 2015). By performing slowed down care Mrs. Jones was able to be an advocate for her patient and seek out other forms of support to help her let go of her grief, stop experiencing pain, and peacefully die. Hannig describes what Derianna, a volunteer for End-

of-Life Choice Oregon, calls “loving someone out.” To “love someone out” means to actively engage in behaviors that help someone move “over the threshold between life and death” (Hannig, 2023: 199). In listening to her patient’s experience of pain and life history Mrs. Jones was able to love her patient out and help her engage in behaviors that allowed her to cross the threshold into death. While Mrs. Jones’ patient didn’t experience physical recovery, she did experience emotional and spiritual healing through the help of Mrs. Jones and the chaplain. Without the care that hospice provided, this patient would not have been able to forgive herself for her experiences and pass peacefully.

Relational Healing

Healing within hospice is not only about healing the personal fragmentations, but it’s also about healing the relationships between people. To love someone out and be an advocate for them in the end-of-life, hospice professionals give attention to the importance of relationships within the patient-family unit. Mrs. Jones shared with me another experience of helping her patient to heal emotionally and socially. This patient had two sons, however after family disagreements they had not talked in 30 years. After expressing this estrangement Mrs. Jones worked to find a way to contact the two sons. The family was able to get on a group Facetime call, during which, the patient passed away. Once again Mrs. Jones was able to provide slowed down care and advocate for her patient’s needs in a way that helped to provide healing of family relationships. Having this healing reconnection with her sons, the patient was able to peacefully pass away.

Hospice care provides emotional and spiritual healing for individual patients and family members while also creating opportunities to heal relationships between members of the patient-family unit. Hospice care’s extension beyond standard biomedical practices allow care

professionals to engage with the patient past their disease to truly understand the complexity of the patient's experience. In doing this, an optimal healing environment is created. Through slowed down, non-biomedical practices, hospice can create good deaths for their patients.

Good Death Through Hospice

A good death refers to the idea that when people are given choices and are able to act in response to those choices, they can craft an experience of dying that is considered good and satisfying to them. A good death becomes a lived experience when a dying individual enacts agency through making choices about their end-of-life experience. Mrs. Wells demonstrated this in chapter three through her commitment to discussing the end-of-life desires with her patients. She asks her patients how medicated and conscious they would like to be, their pain management expectations, and their wishes concerning their family. In asking these questions Mrs. Wells gives her patients the opportunities to craft good deaths for themselves by being active agents in their end-of-life periods.

When I asked Heritage Care Hospice nurses about what good death meant to them and how they understood this concept within hospice care, they each expressed a unique perspective that highlighted the ability of hospice to contribute to a good death. Mrs. Jones emphasized the importance of alignment for a good death. Mrs. Jones believes that the mind, body, and spirit need to be in alignment for an individual to pass peacefully. Mrs. Jones works to assist her patients in creating this alignment through care activities such as identifying unresolved grief or re-connecting estranged family members. Mrs. Jones' commitment to helping her patients prepare not only their bodies, but their whole selves for death contributes to their creation of good deaths. Mrs. Jones can engage in this kind of care work because hospice is holistic care that

provides patients with an interdisciplinary care team through which all of the needs of the patient-family unit are met.

What makes a death good varies greatly depending on each person's previous experiences with death and their cultural expectations about the proper ways to die. In Cain and McCleskey's exploration of the definition of a good death they found that constructions of a good death varied depending upon the social groups that one was a part of such as race, ethnicity, gender and education level (Cain and McCleskey, 2019). The social groups that individuals inhabited influenced their experiences with death and health care and therefore shaped the individuals' perceptions about what a good death would look like (Cain and McCleskey, 2019). In Desjarlais's exploration of the end of life among Tibetan Buddhist in Nepal he described dying as an active project and a collaborative "unfashioning of the self" where the living must help the dying pass away by cutting them off from the world (Desjarlais, 2015: 655). Western ideals of a good death involved pain relief, acceptance, and the ability to mend relationships (Cain and McCleskey, 2019). These ideals were re-iterated by De Jong and Clarke's study of good death stories in Canada which emphasized death with community, in desired locations, and free from pain (De Jong and Clarke, 2009). While good deaths can take many different forms there is no good death without help from the living. The family members or care givers must be willing to help the dying individual fulfill their wishes to create a good death.

Hospice care produces professionals who seek to contribute to the creation of a good death in their patients through the commitment to patient-centered care. Hospice care in the U.S. context can provide relief from pain through regulated medications, assisting the patient and their family with accepting the upcoming death, and as Mrs. Jones demonstrated, they can also contribute to the mending of relationships which allows people to feel peace in passing. The

whole person healing that hospice can create allows for the creation of good deaths through hospice services. When people feel connected, listened to, and healed they can pass peacefully.

For many people, a good death includes retention of the ability to make decisions about one's care and end of life period. Hospice allows patients to retain their agency through care professionals that put their opinions aside and make decisions based on the patient's desires. Mrs. Rodgers expressed the struggle she experiences when a patient desires a different end-of-life experience than she believes would be the best option. Mrs. Rodgers exemplified her struggle through the story of a patient who wanted to be extremely medicated. The patient had been fighting cancer and was quickly entering the active dying period. The patient asked Mrs. Rodgers to medicate her to the point where she would be unconscious. Mrs. Rodgers struggled with this because she knew the patient's family was coming to town and thought that being "as lucid as possible" was a better option so that she could interact with her family. Mrs. Rodgers explained that she worked through this struggle by explaining to herself that it was not her own death that was being crafted, but the patient's death. Even though she disagreed with the decision she medicated the patient to the point of unconsciousness and explained "What I wanted and what she wanted were two different things, but at the end of the day, it had to be what she wanted because it was her death." Providing a good death for patients is not always easy and it does not always align with care providers desires or opinions, however hospice care's patient-centered care ensures that the patient is able to create the kind of good death that they desire.

Good deaths through hospice are possible through and simultaneously contribute to the healing that occurs through hospice care. Without healing care, such as what Mrs. Jones does by helping her patients find alignment, there cannot be a good death. The healing care begins with the patient but ends with the caring of the family after the creation of a good death. When Mrs.

Wells described her experiences with good deaths, she emphasized the importance of clear communication with the patient and family regarding their wishes and her commitment to collaborative care. Instead of "throwing new medications left and right" Mrs. Wells sits down with the patient-family unit and gets their perspective on how they would like to move forward with their care. She encourages the families to be advocates for what they want to happen because they know the patient better than she does.

Mrs. Wells described one patient-family unit that she had a significant bond with which resulted in a good death. The patient was an older man with lung cancer who clicked with Mrs. Wells because of her country upbringing. During her visits they would talk for a while and then the patient and his wife would give her things from their garden. On the day the patient died Mrs. Wells arrived at the house and recognized that the patient was actively dying. She stayed at the patient's house while he slowly slipped away. During that time, she brought popcorn to the family, and they were able to enjoy the snack together. As the patient was passing, his family shared that popcorn had been his favorite snack and that it was fitting that they were all there eating it together. The patient peacefully passed, and Mrs. Wells was there to help the family through the active dying period. Mrs. Wells' story demonstrates the ability of hospice care to provide emotional healing care in the midst of grief and loss. The family members of the patient were able to experience and craft a good death through Mrs. Wells' thoughtful care and commitment to the patient-family unit.

The creation of a good death in hospice is produced through affective care that affirms personhood and creates space for whole person healing. Standard biomedical health care systems do not prioritize the personhood and whole-body healing of patients because the system is based on finding cures and evading death. When death is something that is open, engaged in, and

worked through, people can create good deaths for themselves. Hospice care is a form of biomedicine that treats the patient and their family as a unit who deserve whole body caring. Hospice is a medical practice that lays out blueprints for how standard health care systems can be improved to better care for patients and their families.

How Hospice Can Be a Model for Biomedical Care

Biomedical care has transformed the way that people experience life. Its focus on treating the body's ailments through the knowledge of biology has provided cures and healing for ailments that used to be death sentences. Biomedicine has been critical to the way that we provide care for dying and sick people, however, it is time for care practices to extend beyond the limits of biomedical care. In anthropologist Sharon Kaufman's ethnography on American hospitals, she details the contradictions in hospital care that create unsatisfying and undesirable deaths. Patient autonomy in hospital settings is constrained by "hospital rules, reimbursement mechanisms, and standards of care" (Kaufman, 2005: 28). In hospitals where biomedical care is being provided, people have limited autonomy that does not allow them to experience death in the way that they desire. Death in the hospital setting is "rarely spoken of or foreseen until shortly before it occurs" (Kaufman, 2005: 28). The inability to openly discuss death limits the time that people have to process death and make decisions about how they want to experience dying. Kaufman explains that "hospitals are not structured for the kinds of deaths that people claim to want" (Kaufman, 2005: 29). The focus on extending life until there is nothing left to be extended prevents people from crafting desirable deaths.

Hospice care organizations must wrestle with sitting between biomedical and holistic forms of care. Deborah Gordon explains that biomedical care understands itself as being universal and above nature. Through the Western cultural logics of biomedical care, we have come to believe that avoiding death is not only possible but the best option (Gordon, 1988). Alternatively holistic care perspectives seek to incorporate all aspects of an individual's well-being. This involves a prioritization of the whole person's well-being over a disease process. Biomedicine and holistic care are not incompatible, as hospice care demonstrates, however they

take different approaches to identifying and dealing with patient's health. Hospice care has and will continue to strike a balance between these two care perspectives. Hospice care uses advances in biomedicine to treat their patients' pain symptoms, but it does not subscribe to the belief that medicine can overcome nature and avoid death. It is through the inclusion of a holistic perspective that hospice care provides patients with end-of-life care that goes beyond the biology of dying. When death is not something to be avoided but something to be accepted, care shifts to focus on the comfort of the patient, in which, the end-of-life experience is better. Dying individuals deserve forms of care, like hospice, that allow them to have greater agency, more time to process death, and proper structures to support them in crafting good deaths.

Biomedicine is important for its ability to explain the body in biological terms and find treatments to diseases. The issue with biomedical care is that the problems that people face are not, and never have been, defined only by biology. People face diseases and deaths that are compounded by structures in society. Holmes et al. explain that when physicians don't address social factors they can misdiagnose and cause harm to patients (Holmes et al., 2020). While the authors were talking about non-hospice health care, their statements help us to understand the ways that medical care needs to be expanded beyond biomedically focused care. Hospice patients are more than dying individuals. They are people going through unique end-of-life periods which are affected by their life histories and positions in society. Hospice care's intention to treat the patient instead of the disease allows them to care for the person, provide a good death, and engage in a better form of health care than biomedicine alone can provide.

Hospice as a model of going beyond biomedicine

Hospice care is a form of end-of-life care that goes beyond the confines of biomedicine because of its intentionality in combining biomedical care and holistic forms of care that provide

for the emotional, spiritual, and relational needs of the patient-family unit. Medical care in the U.S. has the opportunity to incorporate holism into its biomedical approach to care. Hospice care can be used a model for how standard medical care can become holistic and extend beyond the boundaries created by the logics of biomedical care through incorporating a patient-centered nature, commitment to affective care, and ability to engage in compassionate presence.

Hospice care's patient-centered nature was demonstrated by the Heritage Care Hospice nurse's commitment to their patients' needs and wants. Mrs. Wells, a nurse, emphasized her willingness to accommodate patients by having intentional conversations with her patient-family units to get to know them better and hear about what they expected in the end of their lives. Mrs. Wells' intentionality allows her to create a schedule of care that suits that patient-family unit's needs and wishes. With some patients she described engaging in conversations over food while with others she helped them maintain their appearance. Mrs. Wells also engaged in non-verbal actions that demonstrated patient centered care such as providing popcorn to the family members of one of her hospice patients. Mrs. Wells took time to sit with the family and engage in an action that reminded them of their dying loved one. Tanco and Bruera, both palliative care researchers, explain that to have successful communication that puts the patient at the center of the care and maintain patient dignity, health providers must have an empathetic approach using non-verbal techniques to create trust (Tanco and Bruera, 2020). Mrs. Wells is able to provide person-centered care by guiding the patient-family unit in creating an end-of-life care plan and then continuing to engage with them through meaningful conversations and actions. This allows her to properly respond to the patient-family unit's needs and desires during the end of life. A commitment to patient-centered care can be developed in standard biomedical spaces if medicine begins to recognize patient needs other than the physical needs related to disease and healing. As

Seth Holmes explains, physicians need to "expand the frame" when trying to understand patients' experiences and needs (Holmes, 2019). Instead of focusing mainly on a disease process and extending life, medicine needs to expand its view to understand the structures that people interact with that influence their experience of health and health care. When the focus is the whole person and how they interact with structures in society, physicians can practice patient-centered care that prioritizes the full well-being of the patient.

Hospice care engages in affective care that is relational in its nature. The stories of Mrs. Dean and Mrs. Carter exemplify the dramatic effects of having a relationship with one's caregiver. Both women have been able to experience physical healing through the care that they received in hospice. The women have deep relationships with their hospice care teams which allows their caregivers to provide more personalized physical and affective care. While talking to Mrs. Wells she described the importance of knowing her patients and having a relationship with them. She explained that with some patients she engages in physical care acts such as braiding their hair, but with Mrs. Dean she could "just sit and talk with her for 30 minutes, and she's so happy." Mrs. Wells was able to discover this because she engages in conversations with her patients that don't pertain to their physical health. She described asking questions such as "Do they like games? Do they prefer reading? Do they prefer having their nails done?" By engaging in this kind of affective care Mrs. Wells, and other hospice nurses are establishing relationships that help them to provide higher quality care. Mrs. Wells' acts of care demonstrate Tanco and Bruera's idea that physicians are able to find nuances in their patients' care preferences, values, and fears when they have an established relationship (Tanco and Bruera, 2020). Mrs. Dean and Mrs. Carter were able to experience higher quality care that resulted in a physical health rebound because they had care teams that created relationships with them and cared for more than their

physical symptoms. Like the inclusion of patient-centered care in standard biomedical spaces, when physicians expand their frame to include the whole patient and the structures that they are a part of they will be able to better understand the care that patients need. While physical care is often needed most, other forms of affective care such as social work, or "just being with" can meet the patient's needs and provide a better experience of care where whole person healing is possible.

Hospice care professionals engage in compassionate presence while providing caregiving services, which results in personhood care and whole-body healing. Palliative care professor Christina Puchalski explains compassionate presence as "not just awareness of the presence of the other person, but also of the transcendent in the relationship between the clinician and the patient/and or family" (Puchalski, 2020: 94). In Puchalski's explanation of compassionate presence she refers to transcendence in a spiritual or religious sense, which is important for some patients, but we can also think about transcendence as meaning that the clinician-patient/family relationship can go beyond its expected limits. Within the context of the biomedical care system, the clinician-patient/family relationship is bounded by the expectation that doctors treat or cure diseases. This relationship can but is not expected to extend past those boundaries. Hospice care has demonstrated that when a caregiving relationship includes a level of transcendence, the patient-family unit experiences better care, affirmation of personhood, and whole person healing. Puchalski explains that to engage in compassionate presence caregivers must engage in behaviors such as "deep listening, curious inquiry, perceptive reflections, the use of silence in patient communication, and assessing for spiritual distress" (Puchalski, 2020: 95). The stories of both hospice caregivers and patient-family units have repeatedly exemplified the commitment to engaging in compassionate presence. Deep listening and assessing allows for the kind of care

that prioritizes the whole person. When the whole person is treated, the patient-family unit can experience mental, emotional and relational restoration. Compassionate presence is possible in hospice care because it does not view bodies and health with the same approach as biomedical care. Hospice care's approach expands the frame that the patient is viewed within. Patients are not treated based on disease processes, but on their needs. Compassionate presence can be incorporated into standard medical care if the system will commit to practicing a kind of care that Lerer describes as "slowed down care" (Lerer, 2015). By slowing down care, providers will be able to engage in patient-centered care that prioritizes relationships and promotes compassionate presence. Instead of rushing patients through the medical system, health care needs to be about caring for the whole person in a personalized way.

Hospice care is not a perfect form of medical care, but it is a model that can be used to transform mainstream medical practices to provide better care for patients. Incorporating interdisciplinary teams into health care will help prioritize the whole person while not taking away from the specialization of care providers. Acknowledging that patients are more than their diseases allows providers to engage with patients in a way that promotes relationships which create opportunities for better care. Most importantly the care provider needs to expand the frame, as Holmes suggests, recognizing that their patients inhabit social roles within a specific social space. Health care needs to extend beyond biomedical care so that it can provide a better form of care to the whole person.

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