An Exploration of End of Life Care for People Experiencing Homelessness

Melanie Kim

Undergraduate Honors Thesis

Department of Anthropology

Brown University

Providence, RI

April 15, 2023

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To all of the service providers who work with people experiencing homelessness. Your passion, love, and dedication is an inspiration.

Acknowledgements

I owe my interest in this topic to Professor Irene Glasser. It was her class on the Anthropology of Homelessness that first introduced me to the study of homelessness, as well as the entire field of anthropology. Through her instruction, I found a deep passion for this field: it centers individual voices and stories, unearths the wrongs in society and its structures, and explores strategies to address these wrongs with intention and compassion. To Professor Glasser for her endless knowledge, her kindness, and her warm heart, I am forever grateful. I owe so much of this thesis to her guidance, her wisdom, and her experience in the field. Thank you for being with me every step of the way!

I want to thank my parents for their love and for the way that they raised me in learning to listen to others and to uplift other stories. Thank you for always knowing how to make me laugh, for picking up my many phone calls home, and for helping me navigate this world with wisdom and kindness. I love you a million!

To my dear friends (and my brothers Joel and Micah) who laughed with me through late nights of thesis writing, who checked in on me, who fed me, and encouraged me…thank you! To new friends and old, my life is so much better because of you. I am so grateful for the time that I got to spend with each of you! I love you all dearly.

To Professor Smith, thank you for really making me think about whether I should write a thesis or not. You ensured that this was a topic and a process that was buoyed by my love and interest in the topic. I still remember my first meeting with you when I said vaguely that I thought I might want to write a thesis, and you told me that I should not do it for the title itself, but because I cared about it enough to write it. That stuck with me, and I know it helped guide me towards this topic, which is close to my heart.

To Professor Mason, thank you for provoking thoughts on topics that I might otherwise never have studied in such depth. Your class on Bioethics and Culture was truly amazing, and I am grateful that it led me to discover the seed of an idea for this thesis.

To Professor Carter and the “teasis slay writers,” thank you for welcoming me into a little community even though I joined a semester late. I appreciated the thoughtful feedback and the space to commune over our thesis struggles. We did it!!

And most of all, I want to thank God for guiding me in this process, for giving me the resources and the heart to pursue a thesis on this topic. His faithfulness and love have been so constant through what has truly been a whirlwind of a year.

Introduction

I. The "Why?"

In October, Mathewson Street Church hosted their annual homeless memorial service. When I arrived at 11:05 a.m., most of the long tables were already full with seated people, and the room hummed with the buzz of quiet conversations. The tables were decorated with little sprigs of evergreen and there were some tasteful lights along the stage at the front of the room. On the right side of the room, there was a cameraman with a giant tri-podded camera and the logo of a news station plastered on its side. The room hushed as the first speaker rose to the stage. She introduced the event and then leaning forward, with urgency in her voice, she reminded us that these people we were honoring today were not just homeless people. They did not choose who they were born to or what circumstances they were born into; they were experiencing homelessness because our government failed to provide for their basic needs. This event was a time to honor them, to remember the love they had shown and the memories that they had left behind. We would not let their names die in darkness.

A man from Amos House read an excerpt from a children's book on grief by Margo Heegaard. In it, the characters, Small and Large, looked up at the stars on a dark night. The stars had died long ago, they said, but they still shone brightly. And just like the stars, love doesn't die; it goes on after death.

Someone else read aloud a poem from Oriah Mountain Dreamer's *The Invitation*:

> I want to know if you can sit with pain, mine or your own, without moving to hide it, or fade it, or fix it…
> It doesn't interest me to know where you live or how much money you have. I want to know if you can get up after the night of grief and despair, weary and bruised to the bone and do what needs to be done to feed the children.

> It doesn’t interest me who you know or how you came to be here. I want to know if you will stand in the center of the fire with me and not shrink back (excerpts from Mountain Dreamer, 2006).

The cameraman packed up to leave, just as people began to rise to the stage to read the names of those who had died in the last year.

The room grew quiet in a different way, a breath-held, heavy kind of quiet, interrupted only by the occasional sniffle or cough. Everyone’s attention was riveted to the front, each of us listening to the halting steps of another person climbing to the stage holding a scrap of paper, pausing before the microphone to say a name. Each name, each wavering candle lit, and I kept thinking about how many stories each of these people left behind, how many memories, how many loved ones.

Sometimes someone only spoke the first name of a person. Sometimes people stood in front of the mic, holding back tears, unable to speak for a few seconds. And when they finally did, their voices quivered with emotion. One woman went up two times, and each time she said several names. Others said the names of family members: cousins and children. There were so many names. 42 one after the other. 42 people named at this ceremony who had died in the last year. Undeniably, there were more who went unnamed. It was the worst feeling when a name was read and somebody said, “what? What?” in muted shock or “oh my God. I didn’t know.”

In the pain, I could feel the love in the room. People cried and hugged each other, squeezed hands and exchanged whispered words of comfort.

I was hit by a reminder of why I am doing this thesis. People experiencing homelessness deserve the right to have their experiences heard and known. We can say in the academic setting that they do not seem to think often of death or planning their deaths, but they are surrounded by it. They are losing friends and family and loved ones, sometimes so many that they scarcely have time to grieve. Death is on their minds because they are reminded of it constantly, fearing it and dreading the toll it will have on their hearts. They deserve the right to be housed. They deserve the right to be heard and listened to. They deserve to be seen, to be known and loved, to be told that they are not alone in their darkest hours. They deserve to be remembered.

I included this recounting of my experience at the homeless memorial service because it helps to frame the importance of the topic of end of life care for people experiencing homelessness. The focus of this thesis is an exploration of the landscape of end of life care for people experiencing homelessness from the perspective of the service providers who offer them care. Through the course of this thesis, I will examine how the U.S. healthcare system responds to homeless people at the end of their life, and the specific challenges which organizations and individuals face as they try to provide end of life care to people experiencing homelessness. I will also explore how the organizations providing end of life care for people experiencing homelessness view their goals of care, and how these align or do not align between different organizations or facilities. Ultimately, I hope that this thesis emphasizes the strengths of existing systems, but also offers insight into specific policies and structures that might be changed to improve access to end of life care for people experiencing homelessness.

II. Background

Globally, only 14% of those in need of palliative care receive it, mainly due to barriers to care, which include family related problems and a lack of programs, policies, and public awareness (Stajduhar et al. 2019). There is a greater prevalence of health problems among people experiencing homelessness, with mortality rates three to four times higher than the general population in North American and European countries (Zerger et al. 2009; Podymow et al.

2006). The mean age of death among single homeless people is between 34 to 47 years (Shulman et al. 2017). People experiencing homelessness have higher rates of chronic conditions, acute illnesses, and behavioral health issues compared to their housed counterparts, which contributes to earlier mortality and poor health ("Health Insurance at HCH Programs, 2020" 2021). People experiencing homelessness also often have a positionality which exposes them to greater structural vulnerabilities (Stajduhar et al. 2019). This includes experiences of racism, histories of trauma and violence, social isolation, stigma, impairments, mobility issues, disability, and interactions with the criminal justice system (Stajduhar et al. 2019). The majority of homeless people have dual diagnoses of substance misuse and mental illnesses, as well as other comorbidities (Podymow et al. 2006; Hudson et al. 2016). They rely upon hospitals and emergency departments to address their health needs and, in North American and European contexts, the frequency of in-hospital deaths is around 34% to 59% among homeless individuals (Podymow et al. 2006; Zerger et al. 2009).

In 2022, there were 582,462 people experiencing homelessness in the United States, about 18 out of every 10,000 people in the United States ("The 2022 Annual Homelessness Assessment Report (AHAR) to Congress" 2022). Four in ten people experiencing homelessness were unsheltered (i.e. places not meant for human habitation). While the number of individuals experiencing homelessness has remained largely static between 2007 and 2020, the numbers of individuals experiencing chronic homelessness has surged by 43%, even though homeless service systems have expanded to serve more people; this is because there has been more focus on resources for permanent housing rather than temporary shelters ("State of Homelessness: 2022 Edition" 2022). In Rhode Island, there were 1,577 individuals experiencing homelessness in 2022, which is about 14.4 people for every 10,000 ("The 2022 Annual Homelessness

Assessment Report (AHAR) to Congress" 2022). A data source from 2021 found that 108 people slept outside because all shelter beds were filled ("SOH: State and Coc Dashboards" 2021).

There is currently no national data that definitively identifies the number of older people experiencing homelessness (Hall 2022). The Annual Homelessness Assessment Report (2022) did report that there are 444,041 people experiencing homelessness who are over the age of 24, which is 76% of the total population of people experiencing homelessness. Additionally, researchers anticipate the population of adults experiencing homelessness who are 65 years and older to more than double by 2050 (Sermons & Henry 2010). Culhane et al. (2019) found the rising elderly homeless population to correlate with the specific birth cohort of post-War baby boomers, born from 1955 to 1965. Based on data from Boston, Los Angeles County, and New York City, researchers have found that the shelter population aged 55 and older has been increasing consistently since 2011 (Culhane et al. 2019). Specifically for individuals aged 65 and over, researchers project tripling in numbers by 2030, and do not see a leveling off of the aged homeless population until 2025, which aligns with the end of this age cohort's life span (Culhane et al. 2019). This points to the relevancy of research on end of life care for people experiencing homelessness, particularly given the continuation of, as Culhane et al. (2019) describes, "unprecedented levels of homelessness among the late Baby Boom cohort from late middle age into older age."

The number of people over the age of 62 was 118 in 2022 in Rhode Island. Perhaps the number does not seem too large, but when we consider that this is the number in one of the smallest states in the US, there are much greater implications for other states who have higher numbers of people experiencing homelessness. Furthermore, as the aging homeless population continues to increase, the need for end of life care will continue to grow (Sumalinog et al. 2016).

For clarity, a delineation of the difference between hospice, palliative care, and medical respite may be important to keep in mind. Hospice is a holistic program of care to support terminally ill patients and their families, which focuses on pain management rather than trying to cure a patient's illness ("Hospice," 2022). While palliative care also focuses on quality of life and pain management for patients with life-threatening illnesses, it *can* have curative intent (de Veer et al. 2018). Medical respite care is acute and post-acute medical care for people experiencing homelessness who are too ill to recover on the street but not ill enough to be in a hospital; this can include terminally ill patients, but also those with severe and more short-term illnesses (Zerger et al. 2009).

There is a lack of available services of palliative care for people experiencing homelessness (de Veer et al. 2018; Hudson et al. 2016). This includes a lack of physical locations and social workers trained to provide the ADL care required at end of life, but also a lack of services, such as spiritual care or psychosocial care, which are a critical element of palliative care (de Veer et al. 2018). Patients experiencing homelessness often have limited access to palliative care and are seen as too much work for a medical worker to care for because of the complications of unpredictable behavior, unknown medical histories, and unstable access to food, housing, and transportation (de Veer et al. 2018; Hanssman et al. 2021; Shulman et al. 2017). Working with populations experiencing homelessness requires greater integration and communication between hospice, housing, and social services: in other words, a more person-centered approach to care (Shulman et al. 2017). Stajduhar et al. (2020) advocated for social workers to undergo more palliative care training, as these individuals are uniquely positioned in consistent and trusting relationships with people experiencing homelessness; however, this strategy risks putting greater emotional stress upon social workers, further blurring the line between formal and informal caregiver and social worker (Stajduhar et al. 2020). On the other hand, Hanssmann et al. (2021) argued that it is health workers, rather than social workers, who ought to be more familiar with federal, state and local programs for housing and other basic needs.

I chose Rhode Island as my field of study because of my familiarity with some of the service providers to people experiencing homelessness. This was facilitated through connections which Professor Irene Glasser has with this community, as well as my work with the student-run club Housing Opportunities for People Everywhere (HOPE). As a member of the advocacy and outreach team of HOPE, I was somewhat familiar with state policies, shelters, social workers, and community based organizations in Rhode Island. Additionally, being in Rhode Island allowed me the chance to meet with a couple of my interviewees at their place of work. Rhode Island is also a unique location of study in terms of end of life care, particularly given the fact that the second hospice in the entire United States was founded in Rhode Island in 1976, just two years after the very first hospice was opened in Connecticut (Friedrich, 1999). As my interviewees identified, hospice had been present on the east coast for over 40 years, and this raised interesting trends in terms of the reach of knowledge about end of life care.

This thesis works to fill a gap in the literature: as Klop et al. (2018) stated in a systematic review of palliative care for homeless people, there are almost no details about individuals experiencing homelessness who completely avoid care. While my research does not examine this issue particularly, by interviewing a broad range of individuals, especially those involved in various community based organizations, it gave me a view into people who might not have engaged with the medical system. My research also provided a view into the perspective of service providers who provided end of life care to people experiencing homelessness, adding to existing literature on the topic. My interviewees differed largely from those identified in the literature because many of them were fairly aware of the particular struggles and barriers which people experiencing homelessness at end of life face; yet, they still expressed how they did not feel equipped or able to address their patients' and clients' needs. This was due to a lack of knowledge, often self-described, but more significantly to a lack of resources to address the needs of their clients and patients. My thesis also extends these experiences of end of life care to the larger population in the U.S., and explores what policies, bureaucracies, and structures communicate about the specific valuing of human life.

III. Methodology

Study design and participants

I conducted qualitative interviews with individuals who worked with people who are homeless and appear to be near the end of their lives (sick and elderly) between November 2022 to February 2023. These included physicians, outreach workers, social workers, directors of community based organizations, hospice care workers, and chaplains. I chose to conduct qualitative interviews in order to center the voices of these individuals and to allow for more flexibility in topic matter. I identified key informants through experience with local organizations addressing homelessness in Providence. Emails or phone calls were made to each of the potential participants to inform them about the purpose of the study and ask for their participation.

I also conducted a review of existing literature to better understand the general landscape of end of life care for people experiencing homelessness. This included definitions of palliative, hospice, and end of life care, statistics on negative health outcomes for homeless individuals, and available facilities. The main focus of the literature review was to identify barriers to end of life care, both through the lens of people experiencing homelessness and end of life care workers.

I interviewed sixteen individuals: an office manager at a healthcare governmental organization, a CEO of a social services organization, an associate professor at the School of Public Health, a director of integrated care management at a federally qualified health center (FQHC), two housing specialists at a federally qualified health center (FQHC), a director at a healthcare governmental organization, a director at a community based organization, two chaplains at a hospice center, a psychiatrist at a behavioral health center and community based organization, a social worker at a hospice center, a physician at a federally qualified health center (FQHC), a social worker at a community based organization, a qualitative researcher, and a director of outreach and communications at a church. Collectively, these individuals represented nine different organizations in Rhode Island.

At the end of each interview, I asked: is there anyone else who you think I should speak to about this topic?

The following are a list of contacts mentioned:

- A chaplain from a hospice center identified other chaplains and social workers at their workplace.
- A CEO of a social services organization identified a physician in primary care with people experiencing homelessness and a director of a governmental organization.
- A qualitative researcher identified a social worker at a community based organization and another researcher.
- A psychiatrist identified a physician in primary care with people experiencing homelessness.

- A qualitative researcher identified a hospice center and a CEO of a social services organization.
- A physician at a federally qualified health center (FQHC) identified a palliative care group in RI.
- A director of integrated care management at a federally qualified health center (FQHC) identified a community health worker at their federally qualified health center (FQHC), as well as a shelter and a community based organization.
- A director at a healthcare governmental organization identified another staff member at their organization and a director at a shelter.
- A social worker at a hospice center identified a chaplain at their organization.
- A director at a community based organization identified an outreach director at a church.
- An outreach director at a church identified a community based organization.
- An office manager at a healthcare governmental organization identified several community health centers.

Nearly every participant had an idea of someone else I should contact, whether it was a specific organization or a person; oftentimes, they provided an email address or even wrote an introductory email to connect me with an individual. My original list of planned interviewees did not include most of the participants who I ended up interviewing, and this highlights the breadth of collective knowledge which these service providers share.

At times it was difficult to get into contact with individuals, simply because of how busy they were, but I found that the great majority were very willing to speak with me. Many emphasized the importance of this topic, and happily directed me to other resources where I could learn more about the topic. Oftentimes, introduction emails would include a section which said “so-and-so recommended that I speak with you” or many times, my interviewees offered to create an email chain linking in someone else who they thought I should speak with.

I had the privilege of access through connections which Professor Glasser helped me make, as well as connections I made through past work with HOPE through advocacy, meal sites, and outreach programs. I also want to acknowledge the privilege of being a Brown student, and how the name of the university likely offered me greater access to different individuals.

Data collection

Semi-structured qualitative interviews were conducted with participants at a location determined by the participant, or over Zoom if in-person interviews were not possible. The interview guide included open ended questions addressing the delivery of end of life care and specific challenges and joys of providing such care. Interviews were audio recorded and transcribed with Otter.ai and were approximately 30 minutes in length.

My central guiding research questions focused on two main trains of thought: Firstly, what is the landscape of end of life care for people experiencing homelessness in Rhode Island?

a. Please tell me about the work you do with people experiencing homelessness.
b. What kinds of services do you provide for critically ill or elderly people who are or have been homeless?

And secondly, how do service providers go about providing this care?

a. What are the challenges of providing high quality end of life care to people experiencing homelessness?
b. What would you like people to know about end of life care with people experiencing homelessness?

   c. How would you describe the working conditions/workplace dynamic for people working in end of life care with the homeless?
   d. What are the greatest joys of providing this care?

My questions were shaped by some preliminary research which I had done for another project on hospice workers in California.

Data analysis

I used Otter.ai to transcribe my interviews and did further editing to fix grammatical errors and mistranscriptions. I created themes based on a thorough review of these transcripts. Transcripts of the qualitative interviews were then uploaded to NVivo where I coded for 22 different themes, including barriers, communication, relationships, and invisibility. After coding, I consolidated my themes into four chapters.

Ethics

This study was approved as an Undergraduate Project by the IRB at Brown University. Especially as I was speaking with people about their patients or clients, I felt it necessary to avoid naming individuals and the organizations which they worked with. These individuals were also deeply honest about the difficulties of providing end of life care, their own lack of knowledge on the subject, and the failings of their organizations or the state policies. To respect that vulnerability, it made sense to maximize anonymity as much as possible. I preserved the specific roles of the individuals and the general type of organization for which they worked in order to highlight the difference in perspectives and experiences based on their particular role or organization.

Additionally, as these interviews were on the topic of death, and many of these individuals had close personal relationships with clients or patients who had passed away, I had to be cognizant about allowing space and being sensitive to when it was time to move away from a more emotion-heavy question. It was sometimes difficult to know when to press in and when to let a question go, especially when I found my interviewee to be giving me critical or valuable information. Discomfort and sadness are not emotions which should be shied away from in interviews on this topic. However, I tried my best to interview with the priority of respect and a desire to understand and not simply to pry; I hope that was communicated to my interviewees. I did realize that I had little capacity to offer any sort of mental or emotional support after my interviews, which was a point of concern. However, I believe the topic and expectations for the interview were made quite clear before each interview. It was also comforting to hear from many of my interviewees that they found their professional and personal networks to be a place where they were able to share emotional burdens.

IV. The Roadmap

Chapter 1 of this thesis will explore the barriers to end of life care for people experiencing homelessness, particularly in bureaucracy and the medical system. It will highlight the complications of working with people experiencing homelessness, as well as the ways in which many factors render their needs invisible. Chapter 2 will explore networks of resources among people providing care to individuals experiencing homelessness. It will highlight informal and formal partnerships, how these are informed by differing approaches to care for this population, and the factors which limit their effectiveness. Chapter 3 will examine the importance of relationships in how the end of life care system is designed, as well as in the way in which service providers build relationships with their clients or patients experiencing homelessness. Chapter 4 will describe how these interviews pointed to larger trends in US culture surrounding death and end of life care, as well as the ways in which people experiencing homelessness often come to accept their own deaths as inevitable. The Conclusion will describe effective models of end of life care and elements to successfully accessing this type of care. It will also summarize major findings and identify recommendations for how particular barriers to end of life care for people experiencing homelessness may be addressed.

At the heart of this thesis is a desire to uplift the lives and stories of people; this is not a topic frequently spoken about, and the invisibility of people experiencing homelessness at end of life only aggravates the lack of care which they receive. My thesis aims to bring to light the particular barriers which providers face as they try to provide end of life care to people experiencing homelessness, as well as the nature of death common among people experiencing homelessness. It also seeks to highlight the strengths of the networks which these providers have created in the face of a system which lacks formal connections to help provide care. I strive to honor the dedication and heart of each of these service providers who I interviewed, who work tirelessly within a broken system to provide care to their clients, patients, and friends. Their personal relationships and friendships demonstrate what it means to advocate and validate; they also show that providing end of life care to people experiencing homelessness requires deep personal relationships and a willingness to fight for a person that goes beyond a formal relationship.

Chapter 1: Barriers and Challenges

"The poor are not only more likely to suffer, they are also more likely to have their suffering silenced" (Farmer 1996, 280).

I. Background

My interviews with end of life care providers for people experiencing homelessness revealed the ways in which the government and the medical system were a part of the silencing of suffering; indeed, in many ways, they were complicit in *creating* suffering. Farmer described this as structural violence, which is "violence exerted systematically—that is, indirectly—by everyone who belongs to a certain social order" (Farmer 2004).

After surveying accessible data from the US. Department of Housing and Urban Development (HUD), the National Alliance to End Homelessness, and the RI Coalition for Homelessness, I found no specific statistics for the aging population of people experiencing homelessness. In the Point in Time (PIT) count, an annual count of sheltered and unsheltered people experiencing homelessness on a single night in January, there is only a category for the number of persons 25+. In Rhode Island, this number was 1,159 in 2022, a number which has risen from the approximately 800 person level where it had been since 2018 (Rhode Island Coalition to End Homelessness 2022). I reached out to a professor at a local college who analyzes the Homeless Management Information System (HMIS) data to ask specifically about the number of homeless individuals aged 60 and older. There were 118 reported individuals in 2022, a drop of over one hundred people from the 229 the year before. That could mean that these 111 individuals were housed, died, or disappeared from the system, but it is not possible to tell which. The HMIS also does not currently have reliable data on the number of people who have chronic or terminal illnesses.

If the numbers of people experiencing homelessness who are elderly and/or ill are undocumented at the state and national level, it is no wonder that this population is often overlooked and unseen.

It brings to mind the concept of “letting die,” which Michael Foucault theorized in his writing, *The History of Sexuality*. He notes a shift during the nineteenth century during which the power of the government to take life was replaced with an ability to actively make live or passively let die (Foucault 1978). He terms it as biopolitics, or the ways in which the government can govern its population by disciplining bodies, with an overarching aim of optimizing life (Foucault 1978). Bruce O’Neill explores this concept of “letting die” in *The Space of Boredom*, an ethnographic work on the downward mobility of Bucharest’s homeless. As Bucharest moved towards a capitalist global economy, it cast aside certain populations to a slow death; this was a pointed biopolitics by the government to relegate the unskilled, poor, elderly, and homeless to lives of hardship and slow deterioration that brought about an early death: “letting die” (O’Neill 2017). By not providing necessary services or support to these populations, the government concealed this population through their exclusion from society and hidden deterioration and death.

This is not to argue that the United States does not have programs and councils in place to address the issue of homelessness. Yet, the lack of data on populations of people experiencing homelessness accuses it of letting these people slip into invisibility. As this chapter explores, the barriers and lack of support and services for this population reveal how the U.S. government values the lives of its citizens in different ways. In many ways, this also implies that people experiencing homelessness are not deserving of the same rights to dignity.

II. Bureaucratic Barriers

As I interviewed people who work with individuals experiencing homelessness, bureaucratic barriers were often raised as a limiting factor for access to end of life care. Often this was at the insurance level, specifically with what medical care Medicare and Medicaid covered. People experiencing homelessness are uninsured at high rates because they often do not qualify for Medicare or Medicaid and cannot afford private insurance ("Health Insurance at HCH Programs, 2020" 2021). With law changes in 2014 which expanded eligibility for Medicaid to include people with incomes below 138% of the Federal Poverty Line, this led to an increase in "dual eligible" people experiencing chronic homelessness, who qualified for Medicare and Medicaid (Wilkins et al. 2014). However, as my interviewees emphasized, specific coverage policies of Medicare and Medicaid often denied individuals care:

> Much of how we provide care is really driven by whatever the current regulations are for Medicare and Medicaid, because they, at the centers for Medicare and Medicaid, provide most of the reimbursement for hospice care in the United States. (Chaplain at a hospice center)
>
> In order to be on hospice, they have to have a terminal diagnosis of six months or less to live…No more interventions can be provided. No more chemotherapy, no more treatments, things like that… So hopefully if a person has Medicare or Medicaid, they should be entitled to getting the services that we offer at no cost to them… nursing visits, CNA visits, all of the stuff that hospice offers, medical equipment, and medications that are related to your terminal diagnosis. What they won't cover is room and board. So if you're discharged from the hospital and you don't have a place to live and you only have Medicaid or Medicare… **nine times out of ten, a facility is not going to take you because Medicare, which is a federal entity, will not cover room and board**. (Chaplain at a hospice center)

Interestingly, reading the policies for Medicare and Medicaid on the official government websites makes hospice care seem accessible; they even state that hospice care is most often provided where the patient is living, including shelters, respite care facilities, etc. (Health Care for the Homeless Clinicians' Network 2018). However, as my interviewees demonstrated, the realities of hospice care access seem to differ widely from these policies.

Thus, it is the very highest level, national insurance policy, that restricts people experiencing homelessness from accessing end of life care. Kaufman (2005) explores the ways in which technologies, hospital procedures, and bureaucracy in the hospital shape dying and restrict individuals to only act within existing systems. It is the idea of the social lives of medicine, that technologies take on their own life and begin to dictate care (Kaufman 2015). This can apply to actual physical technologies, such as mechanical ventilators, which were originally developed to keep patients breathing during surgery. However, they began to take on a life of their own as tools to keep people in comatose states alive, dictating a moral imperative of use and redefining what it means to be "alive" (Kaufman 2015). In the same way, policies like Medicare and Medicaid seem to come alive and dictate care. Medicare and Medicaid drive a revolving door pathway of admittance and discharge for chronic illnesses (Kaufman 2005). Because of specific reimbursement policies with time limits for care, patients are continuously transferred between nursing homes and hospitals in order to maintain their coverage (Kaufman 2005). These processes depersonalize care, demonstrating that the logic of bureaucracy and protocol are much more powerful than any individual voice (Kaufman 2005).

Goldberg et al. (2016) further describes this "institutionalization circuit" where people experiencing chronic homelessness are cycled between street or shelter to institutions. This institutionalization circuit does not offer dignity or the right to make meaningful choices about housing (Goldberg et al. 2016). Yet, there are existing court decisions which obligate states to provide services to these populations in the most integrated settings possible ("Fulfilling the Dream: Aligning State Efforts to Implement Olmstead and End Chronic Homelessness" 2016).

For example, the 1999 US Supreme Court case Olmstead v. L.C. upheld the Americans with Disabilities Act (ADA), declaring that individuals have the right to "live with dignity in community settings that offer them privacy, meaningful choices among housing and services options, and opportunities for social connections with family members and other community members" (Goldberg et al. 2016). Yet, my interviewees emphasized that this is a broken and convoluted system, and there is no guarantee that such care is achieved.

> If we have somebody who is elderly and medically compromised and they have physical needs and they're homeless, we would really want to look into a long term care facility and nursing home… And that's very, very hard to achieve because they have to get on the long term care waiver with Medicaid, wait for that to go through, and then the process is very convoluted… The **work around**, honestly, it's like to get somebody to go to the hospital, **hoping** that they get admitted and that the hospital initiates that placement into a long term care facility. (social worker at a community based organization)

Here, the word choices of "work around" and "hoping" are notable. So much of this system is unpredictable, a cross-your-fingers kind of situation, rather than an official and straightforward process. Despite policies which might imply coverage of this population, the reality is much more complicated. A primer released by the U.S. Department of Health and Human Services frequently used the phrase "people experiencing homelessness may fall through the cracks" (Wilkins et al. 2014). Thus, though the U.S. has a system of insurance, it is clear that it fails to make care attainment possible. Henry et al. (2017) also emphasize how hospice palliative care is built upon problematic assumptions: that patients will have an informal support network, stable housing, predictable terminal illness trajectories, and access to healthcare. All of these are often not within reach of people experiencing homelessness.

> If they don't have the shelter part, we really don't have the infrastructure in our state to really meet those patients' needs. It's quite…it's sad. (Chaplain at a hospice center)

> I just don't think there's enough options in the state right now that fit that criteria, being open to somebody experiencing homelessness, and specializing in that end of life care. (Office manager at a healthcare governmental organization)

Interestingly, the critique that my interviewees presented did not extend to the whole nation, but pertained particularly to Rhode Island. This could speak to a lack of knowledge about the functioning of other states’ resources or point to Rhode Island having a unique end of life care landscape that differs from other states. It is perhaps concerning to note that individuals working with this population are not in communication with people doing the same job in other states. Additionally, to the extent of my knowledge, there is no existing literature which addresses this topic.

Individuals involved with the end of life care industry are also aware of the government’s attempts to provide resources to meet this gap in care, mainly through funding opportunities. As a physician at a federally qualified health center (FQHC) described, there are 340B federal grants from Health and Human Services which fund community health centers across the country, and a subgroup within the grant specifically for community health centers who work with people experiencing homelessness. A director at a community based organization also stated that the RI governor has been involved in funding hotel rooms for the homeless this winter, especially with the lack of space in shelters.

Yet, there appears to be different understandings about available funding for homeless service providers. An office manager at a healthcare governmental organization described the process to submit funding proposals as accessible, saying “we do a good job about providing information.” They described email notices to homeless service providers alerting them of funding opportunities, a proposal process that involved a point system of criteria (what type of care is provided, staffing capacity, historic experience, organizational goals) in which the highest ranking provider was granted funding, and occasional financial incentives for organizations to retain high performance staff. Though perhaps on paper there are plenty of opportunities for funding, people actually working at these organizations present a different picture, of a funding landscape that is intensely difficult to navigate.

> And look, funding is so difficult. Most of the shelters are either state run or they are nonprofits, and they rely on the generosity of the community. And they're struggling also. And there's such a spike in homelessness because of the economy… and so many other reasons that it's like sometimes you don't even know where to begin. (Chaplain at a hospice center)
>
> I can't speak to what's going on nationally, if there are other organizations who have established a home for people to go in to pass and to be cared for like a nonprofit or something along those lines, because I really doubt a for profit would ever do something like that. Because what's the benefit? They're not going to get anything from somebody who already has nothing. (Chaplain at a hospice center)

At the root of funding decisions is profitability, which raises several questions: is it profitable to provide care to the elderly and the sick, and specifically to people experiencing homelessness, who often do not have the means to pay for it? More critically, why is this a question that the state is asking? Why does profit matter more than people?

> People know that [providing end of life care for people experiencing homelessness] is the right thing to do…That's not in question ever, but it's a question about… does that make sense financially for the state? What is the **return on investment** for developing those types of programs? So I think that's sometimes the trickier area with providing the justification as to why we need to actually develop those programs. So it's not always enough to say, ‘oh, yeah, this is the right thing to do.’... it’s just providing the facts and the financial details around why this is a **good decision economically for the state** as well. (Office manager at a healthcare governmental organization)

Thus, we are introduced to this larger dialogue between what is “right” and what is “a good decision economically.” This friction is clearly acknowledged, and it is fascinating that it is “people” who know that it is the right thing to do, while it is “the state” that is demanding for a return on investment, for good economic decisions. This word choice by the office manager separates the people who work at these organizations from the government which they serve. In many ways, it feels like a denial of responsibility, an excuse, a cop-out to shift blame. Foucault (1978) once described the power of the state almost as a living and single being: "power has to qualify, measure, appraise, and hierarchize, rather than display itself in its murderous splendor... it effects distributions around the norm" (144). But the state is not a single and living being; a formulation of "the state" and the "power" as such becomes problematic because it loses the face of the individuals who are driving the formation of this power. True, these people are restrained by the structure of the government and the specific organizations which they serve, but it is false, and even dangerous to deny agency and the ability to make choices humanely based on moral right, rather than economic good.

On another note, projected statistics reveal growing shelter and health care costs for the elderly homeless population, with costs in New York City tripling from $150 million to $461 million between 2011 to 2030 (Culhane et al. 2019). Therefore, even if the government refuses to allot more money towards programs that serve this population, health costs will continue to rise.

Interviewees also described how peoples' personal experiences with bureaucratic barriers often act as long term discouraging factors:

> Oftentimes [there are] those who've been unsheltered for a very long time and have particularly lost trust and faith in government…they may have been reluctant to receive medical care or sign up for Medicaid because every time they were offered something, there was another bureaucratic barrier or there was another challenge that happened and they did not get the care that they needed. So they have sometimes, unfortunately, given up. (Director at a governmental agency)

Wilkins et al. (2014) also describes how the enrollment process in Medicaid can impede people's access to care, particularly for people experiencing homelessness who might find it difficult to get mail. Before the passage of the Affordable Care Act, Medicaid required enrollees to reestablish eligibility as often as every six months (Wilkins et al. 2014). This meant that many people experiencing homelessness had difficulty with continuing enrollment in Medicaid because they lacked a stable mailing address or the ability to gather required documents; Wilkins et al. (2014) found that this resulted in some providers finding the number of clients disenrolled from Medicaid to equal those newly enrolled. The passage of the Affordable Care Act required states to increase the reenrollment time to 12 months, but this does not completely remove the barriers to maintaining Medicaid eligibility (Wilkins et al. 2014).

Beyond bureaucratic barriers, interviewees pointed out the lack of available housing options. Most often this was due to a lack of space at shelters or access to affordable housing. In the most recent assessment of RI homeless numbers, 80% of individuals had a bed available to them, but 108 slept outside because all shelter beds were filled ("SOH: State and Coc Dashboards" 2021).

> I've seen a few cases where folks who are elderly may wind up homeless because they've been renting the same apartment for the past 20 years and the landlord sold the apartments and now the rent is sky high, or the new owner wants everybody out. And this person has never had to navigate the housing system. They lived in the same place for a number of years, paying affordable rent. So market rent is not an option. **There's no housing options available**. Typically, it takes anywhere from six months…to like three years…If they're elderly, they definitely have preference. So I would say like six months to like a year. (Director of integrated care management at a federally qualified health center (FQHC))

This speaks to the lack of affordable housing, a topic which my interviewees frequently raised. The timelines for attaining this housing were also very long, even for the elderly. This means that shelters are often the main form of housing support. However, even these were often not viable options:

> There's criteria around who can be in the inpatient unit, which is all regulated by Medicare…the federal government. If the patient doesn't meet criteria for that level of care, there's really not a lot of places for them to go. Our social workers are pretty limited in terms of other organizations that they can coordinate care with. Because there's just not a shelter. There's not a place, **there's no housing for them to get their needs met**. (Chaplain at a hospice center)

This highlights how inpatient units have criteria excluding people experiencing homelessness at end of life. Unfortunately, shelters often were not a housing option either, as shelter rules were not inclusive for those with terminal illnesses or in need of end of life care.

> A social worker from our end will work diligently to try to find like a hotel or something or a shelter, but none of the shelters in our area that I know of, will accept somebody who is at end of life because of the medical equipment, the liability, needing constant care, 24 hour care sometimes. And it's really sad. (Chaplain at a hospice center)

> If you're too ill to be in a shelter, then you can't stay there. The shelter expectation is, you're there overnight, and then you go out during the day and you have to be out on the road until the end of the day. I've had conversations with some shelters and tried to say, let the person stay inside if they're really not able. It's never actually worked out. I have been told that they're willing to try to consider that. But part of me says… they just really don't want to accommodate that. (Social worker at a hospice center)

One can see the amount of effort that these people have put into trying to provide care to their patients. However, even after having specific conversations with shelters, the rules and expectations end up excluding certain populations. As my interviewees said, this is partly due to a lack of capacity for shelters to provide higher level care; however, even when hospice centers are willing to form a partnership and provide necessary services and equipment, shelter rules still exclude people with terminal illnesses from feasibly using their services. This leads me to ask, where are these people supposed to go?

III. Medical System Barriers

A major theme throughout nearly all of these interviews was that of the stigma and discrimination which the homeless population faces, especially on the topic of substance use. These negative interactions act as barriers that prevent many individuals from seeking care. Often unprompted, interviewees explored the stereotypes against people experiencing homelessness and tried to de-stereotype them through the way that they spoke to me and the stories which they chose to tell.

> With the homeless population, we have to take an even more compassionate view…There's such a stigma with people who are homeless. There's such a misunderstanding, oftentimes, of how did you get homeless? Did you choose to be homeless? Are you a drug addict? You know, all of these assumptions that we make about people **without asking the appropriate questions**. (Chaplain at a hospice center)
>
> There are stereotypes that homeless people are chronic alcoholics or chronic substance users and that's why they're homeless. So **it's kind of their fault that they're homeless**. But many times it's more often people who have mental illness, who are not connected to the services that they need. They don't have close family support for themselves to be able to live in the community. They may have a history of… being imprisoned and getting out of prison and not having the resources to get back on their feet and be able to find a home or pay for… a place to live. (Director at a community based organization)

The narrative of stigma and blame undercuts the reality and uniqueness of peoples' experiences. It denies them a voice and works to rest much larger structural problems within the individual. Another interviewee described how this manifested itself in the case of one of their 50 year old clients with metastatic cancer who had been experiencing chronic homelessness, was an alcohol user, a registered sex offender, and had cycled in and out of prison:

> At baseline, he experiences a lot of stigma…He's also getting a lot of **'You did this to yourself' narrative**. So he's been to the hospital and been to various providers and just been treated like garbage, you know? Not just by the doctors, kind of by society in general… It's deep rooted because so much of this bubbles up from… 'you did it to yourself' attitude or 'this person isn't deserving' attitude. (Social worker at a community based organization)

The “you did this to yourself” narrative turns problems with the medical system and the state into a personal problem. It is also deeply rooted in public perception of the homeless as drug addicts and mentally ill, and the ensuing debate about health care as a right or a privilege (Davis-Berman 2016). Davis-Berman (2016) also points to discharge practices of hospitals as ways in which the medical community affirms the stigma linked to this population. This stigma and discrimination is perpetuated by professionals who often label people experiencing homelessness as “aggressive, rejecting, passive, manipulative, norm-breaking, rule-breaking” (de Veer et al., 2018). These findings align with other literature on the topic, which explores several reasons why unhoused people avoid seeking medical care: mistrust of professionals and past experiences of disrespect, discrimination, or stigmatization (de Veer et al., 2018; Hudson et al., 2016; Stajduhar et al., 2019). A chaplain at a hospice center warned of “these assumptions that we make about people without asking the appropriate questions.” This will require much more than a restructuring of the medical system, but a reframing of personal opinion and judgements by medical personnel.

Even for those individuals who did seek end of life care, end of life care options were not often well fitted to this specific population. Many interviewees spoke about strict policies and limiting criteria which did not account for the particular experiences and challenges which people experiencing homelessness face. A qualitative researcher went into some of the specifics of this:

> Often if you're so many minutes late to your appointment, then you can't get seen that day, but it doesn't take into consideration barriers people face with transportation or with not having the ability to charge a phone and set a reminder. (Qualitative researcher)

These conversations illustrate the restrictive nature of medical systems and highlight a common finding of other literature that providers rarely acknowledge how people’s fight to survive influences their abilities to access services; many health care providers seemed to perceive social care needs, like food, shelter, income, and transportation, as falling outside of their responsibility (Stajduhar et al. 2019).

However, in the course of my interviews, I learned about providers within the structures who were willing to fight for their patients. Rather than confront the system itself, physicians acted through person-level routes to advocate for their patients.

> From what I hear from providers, it definitely feels like they're **fighting upstream**. They're doing a lot of **trying to retrofit systems that aren't really designed to meet this need** to work. And so that requires a lot of advocacy and **tweaking and hands-on management of situations** so that people don't get pushed out of systems or of literal places. (Social worker at a community based organization)

It may be tempting to see this as futile, but in my view, this person-on-person approach is effective. It is more a question of how to operationalize this and make it more feasible and sustainable for people to act upon. If care is centered first around the individual, we can work up towards the clinic, medical system, and state, building upon the lessons learned and approaches taken to meet these needs. Literature does address the reality of worker burnout, however, when individuals take this burden of responsibility upon themselves. Stajduhar et al. (2019) describes how healthcare providers went “above and beyond” their job descriptions, going against institutional policies to provide care “under the grid” to patients housed in spaces declared “unsafe” by the medical system, such as single room occupancy hotels, shelters, or supportive housing. This led providers to feel distressed and frustrated, especially as they witnessed firsthand inequities and injustices (Stajduhar et al. 2019). Especially as these responsibilities were often beyond their training and responsibilities, they did not feel qualified to provide this care (Stajduhar et al. 2019). Hudson et al. (2017) also described the huge emotional burdens felt by staff as they came to grips with the fact that a person was approaching end of life. It also leads to a larger question of whose responsibility it is to start an initiative to address these particular barriers. Should it fall upon the providers who engage directly with the patients? Or does their activism take away from the responsibility of the greater medical system and state to engage in large-scale change?

Much of the literature on this subject described how patients experiencing homelessness often have limited access to palliative care and were seen as too much work for a medical worker to care for because of the complications of unpredictable behavior, unknown medical histories, unstable access to food, housing, and transportation (de Veer et al., 2018; Hanssman et al., 2021; Shulman et al., 2017). In the population of individuals who I spoke to, these service providers did not speak about turning away patients because they were too much work. This is also likely due to the nature of the sample of people who I spoke with. Though I reached out to many different types of service providers, the only ones who were willing to do interviews were ones who felt like they had relevant experience and information on working with people experiencing homelessness. Thus, by default, these are not the workers who would say that these types of patients were too complicated to provide care for, and in that way they are unique from the larger population of social workers, providers, etc.

For those people experiencing homelessness who did seek medical care, many had a very late arrival to care. An associate professor at the School of Public Health put it so starkly as to say that some patients wait so long to arrive, that they essentially “come in to die.” Other literature supports this finding (de Veer et al., 2018; Stajduhar et al., 2019).

> This person came in with kidney function that was just terrible… and within 24 hours, this person was completely worsening and dying very, very quickly. That was a very clear pattern of someone waiting to be absolutely unable to be outside…before coming into the hospital. (Associate professor at the School of Public Health)

> I definitely think that it was not the case of the worried well, who are saying, 'Oh, I got a thing and what is this?' It's not like people were coming in early. It's, 'I have this spot or I've been coughing up blood.' 'How long have you been coughing up blood?' 'Six months, a year.' That did happen enough that it doesn't surprise me anymore…I would say more common than not, they've been having it longer than you would expect. (Physician at a federally qualified health center (FQHC))

Other stories also highlight a theme of hidden pain and illness, which introduces a debate of whether this delayed care seeking was simply because people prioritized survival over medical care, or if it was because they weren't offered an opportunity to seek medical care. This is a concern which will be addressed in more detail later in this thesis.

> We had one woman here in the past year that needed to have both of her legs amputated…from the knee down, her legs were just all open sores. So it is amazing how people can really **deny, suppress, ignore** something until it's so huge and then there's no good answer. (Social worker at a hospice center)

A social worker at a community based organization described a patient with metastatic cancer:

> Quite often, **people will be connected past a point where a lot of options are still on the table**…maybe eight or nine months ago at this point, he [the cancer patient] has been…not up to connecting with care. And he finally feels up for connecting with care. Friday, he was like, 'I'm ready.' And so I reached out to a doctor…and I'm really expecting and dreading that he's going to get really bad news. And there's a few folks where **I can see it coming. I can tell they're really, really ill**. And at this point…they haven't yet connected with care despite some gentle nudging. (Social worker at a community based organization)

These accounts highlighted the importance of having someone engaged in ongoing, long term care who knows the individual and can tell when medical intervention is necessary. This is why other scholarly works have recommended engaging social workers or outreach workers, people who work closely and regularly with people experiencing homelessness, in end of life care (de Veer et al. 2018; Krakowsky et al. 2013). And yet, as with any population, engagement and recommendations will not necessarily guarantee care seeking. This would require a much deeper restructuring of the medical system.

Interviewees also described the difficulty of navigating living situations for their clients, particularly in balancing the dignity and autonomy of their patients with practical concerns. One social worker at a hospice center shared a story of a patient with a foot injury who had lost his job and his apartment, and had been told by doctors that he would die soon. His sister in Pennsylvania was receptive to having him come live with her, but he "didn't even want any part of it."

> It's like, **here are our options and none of them are what you want and you don't have any resources**…And this gentleman…. he was really trying to slow the process of leaving [the hospice center]…so it got to the point where I really had to say to him, we have to make a decision… he was thinking that he could get back to working; he was totally unrealistic about how ill he was. (Social worker at a hospice center)

This balance between autonomy and practicality was made even more complicated by split households, in which some members required end of life care, while others did not.

> Sometimes there will be family that will take somebody in but if you've got a parent in elderly housing, they're not supposed to have somebody come and live with them, and so navigating, are we going into a place where the person actually isn't supposed to be?...**It doesn't seem like we really begin to touch the problem**. (Social worker at a hospice center)

A director at a healthcare governmental organization described the difficulty of providing solutions for families and couples within shelter systems. If, for example, there is a couple in a nursing home and then one partner no longer requires a higher level of care, "Where do you discharge that person to? And…how do you coordinate the supportive services including getting to see and be with their loved one?" (Director at a healthcare governmental organization). To their knowledge, there were no apartment style nursing homes that allowed one patient to get services and the other simply to reside there.

A fear of institutionalization often prevented individuals from seeking medical care. A social worker at a hospice center described a conversation with a patient where she was recommending that he go to a nursing home: “he was like, ‘I'd rather go back to prison.’ At least, he felt like that would be a more respectful place to be than being in a nursing home” (Social worker at a hospice center).

For some individuals, this fear included a knowledge of how the system worked, and the inevitable outcome of speaking with someone about their needs. An associate professor at the School of Public Health described a “**pressure** to move to another care setting or to a long term care setting” and how many people might be reluctant to enter the healthcare system, knowing that this would be the “ultimate end result of their consulting.” Other interviewees referenced past trauma, particularly with experiences of incarceration or involuntary hospitalization, and how people avoided nursing homes or inpatient facilities to avoid feeling “trapped” or “cooped up” (Social worker at a community based organization).

> There's been a lot of instances where I've been chatting with someone who was held in the behavioral health unit at the hospital. They were intoxicated and they got picked up and taken there… feeling very traumatized by interactions, feeling traumatized by the security guards. They're being strapped down to beds. People experienced what they characterized to be really significant trauma, and then also let out at a time where buses don't run…the wee hours of the morning. People described these types of instances as being really harmful to them. And…not hearing it once or twice, but **hearing it over and over** from different people…that's probably the biggest narrative that I've been told in Rhode Island. (Qualitative researcher)

This was a grounded fear. As stated above, there is a pattern of an “institutionalization circuit” that cycles people experiencing homelessness from institutions to the street, back to the institution (Goldberg et al. 2016). In my conversations, interviewees also addressed how the lack of options for this population severely restricted the choice of whether or not to be institutionalized.

> [Institutionalized care] might happen earlier with people who have housing insecurity, because there may not be the possibility to safely discharge them to another setting…it's also a population that's at risk of being institutionalized for a longer period and being in long term care or inpatient settings for longer periods because of that lack of outpatient setting that would meet their needs. (Associate professor at the School of Public Health)

Interviewees also identified the hospital as the frequent place where people experiencing homelessness die; in other words, the hospital often served as their only end of life care. This was a trend noted by interviewees in a range of professions: social workers, chaplains, directors, professors, and housing specialists. People described the hospital as "the default" or as there being an "understanding that that inpatient hospice bed may be their last place of residence" (CEO of a social services organization; Associate professor at the School of Public Health). Each interviewee also emphasized that this was not the best setting for provision of care, but that there simply were no other good alternatives.

> The ER is a point of contact for these populations… because they may not have regular health care providers…The providers may not… be really good at providing symptom management and palliative care, so kind of overly aggressive care that will not necessarily improve their quality of life or even length of life. And then there may not be enough space for loved ones to say goodbye and have this quiet and important space to be together. (Associate professor at the School of Public Health)

This reliance upon hospitals and emergency departments to address health needs is a trend noted in literature on the subject (Podymow et al. 2006; Zerger et al. 2009). In North American and European contexts, the frequency of in-hospital deaths is around 34% to 59% among homeless individuals (Podymow et al. 2006; Zerger et al. 2009). An older study in Boston also found that death for adults experiencing homelessness most often occurred in a hospital or residential dwelling; exposure to cold caused only 4 of 606 deaths (Rousseau 1998). This is not to undermine positive experiences which individuals experiencing homelessness have had at the end of life in hospital settings. A chaplain at a hospice center shared a story about a patient who had well-established trust with a hospital team. Rather than go to a hospice center at end of life, it made sense to the patient and the team for her to go to the hospital, a place that she knew well. Other literature also identified shelters or hostel systems as frequent places of death, because these were where individuals had built relationships with staff and felt most comfortable and secure (Podymow et al. 2006; Hudson et al. 2016).

It was interesting that patients experiencing homelessness at end of life in the hospital were sometimes not noted as such. A chaplain at a hospice center described an adjunct service that their hospice center performed at the hospital, consulting with patients at end of life: “it may be that I'm meeting people at the hospital from time to time and I'm not aware that they're homeless.” (Chaplain at a hospice center)

For people experiencing homelessness who did end up being admitted to these institutions (nursing homes, hospitals, assisted living care facilities, etc.), a deep need for freedom often caused them to leave care facilities. A director of a community based organization described a man with a mental illness who was housed in an assisted living care facility, but chose to return to the streets:

> You can't force someone to do something that they don't want to do, but on the other hand, is he able to endure the colder temperatures with winter coming? I think it’s this feeling of claustrophobia, not being able to stay within this building, this space and not having the freedom to do what he wants to do. So, being out on the street gives him that freedom. He can make his own choices about where he wants to go, what he wants to do. (Director of a community based organization)

This raised an important question: how do you keep people who have been chronically homeless engaged in end of life facilities? The interviewee also described another older woman with some health problems who had a room at a shelter:

> **We don't know what happened to her**….Every day, you see her out on the street, walking, walking, walking, walking, and she was used to being outside. But all of a

> sudden she disappeared. **We don't know what happened to her**. There's some speculation that she is in a nursing home, assisted living facility, but we just don't know where she is. But she's a person that really thrived on just being able to get out and move about and walk in downtown Providence. And I don't know… mentally she just needed that. (Director of a community based organization)

It is also valuable to note that this interviewee did not pass judgment on these individuals for choosing to leave care, but understood their need for freedom and the right for people to make their own decisions. Yet, this did not relieve them of worry for these people and a fear over what would happen to them. As the interviewee emphasized twice, “we don’t know what happened to her” and “she disappeared.”

This lack of follow up was something that many interviewees identified as a major barrier to accessing medical care: how people experiencing homelessness fall through the cracks (Wilkins et al. 2014). A chaplain at a hospice center described how a social worker at their facility might work diligently to find a hotel or a shelter that would accept an end of life patient experiencing homelessness, but, as described earlier, shelter rules excluded people at end of life because of the liability of medical equipment and constant care. The chaplain concluded by saying, “I don't know where they go.” As a social worker at a hospice center said, this was a clear demonstration of “los[ing] somebody to follow up.”

Especially for people constantly on the move, it was difficult to secure a consistent form of contact and oftentimes people would simply not turn up to appointments. With no way to remind them of appointments, interviewees expressed frustration about how they could engage people with treatment. A chaplain at a hospice center described a woman who lived in a tent and came to a local hospital for oncology care. The entire team of nurse, case manager, social worker, and chaplain had scheduled a team meeting with the patient but ended up waiting over half an hour, and “the gal didn't show up for her appointment” (Chaplain at a hospice center).

A physician at a federally qualified health center (FQHC) also described the unpredictability of working with this population:

> When I was doing primary care, there would be a percentage of patients who I would see pretty regularly for a number of months, and then I wouldn't see them at all and maybe a year later they might come back. Either they went out of state or they started going somewhere else. But they did show up on… maybe not on the day that they were supposed to, which is fine, but while they were homeless in Providence, I would see them regularly and they might come back a year later or something. The other patients, you see once or twice and they never come back. But I don't have any conclusion currently, of why some patients come back and whether it has anything to do with whether they're homeless or not homeless. (Physician at a federally qualified health center (FQHC))

This lack of follow up also means that most of these individuals do not have well-documented medical histories, which causes difficulty among professionals in recognizing palliative care needs even when individuals do present themselves for care (de Veer et al. 2018).

Technology itself was found to be a barrier to follow up care, particularly with the aging population. As a director of integrated care management at a federally qualified health center (FQHC) described, many of their patients did not have a cell phone or internet access; even when they did, they often needed someone to teach them how to use it.

> [We] have a mutual patient where they don't even know how to program a number into their phone. So any person at [our FQHC] that's trying to outreach them, I always program their number into the phone so that way they know who's calling them. Because they don't know how to do it. (Housing specialist at a federally qualified health center (FQHC))

IV. The Complications of Substance Use

Patients experiencing homelessness are already a complicated population to work with, but when substance use disorders and terminal illnesses were layered on, navigating how to provide effective care and pain management grew increasingly difficult. As an associate professor at the School of Public Health explained, finding the appropriate dosage of prescription drugs to control pain was a delicate balance, especially with patients who had a history of substance use. A social worker at a hospice center also emphasized how many pieces were at play, including the importance of having a regular relationship with a primary care provider. Other literature has described how the complexity of managing palliative care and substance use were seen as barriers that denied homeless individuals from access to basic levels of access to health services (McNeil & Guirguis-Younger 2012). Shulman et al. (2017) found that homeless people would often leave a ward to obtain substances or alcohol. These are particularly relevant findings to this population, as the prevalence of substance use and dual diagnoses of mental illness and substance misuse are significantly higher in the homeless population when compared with housed populations (Hudson et al. 2016).

A physician at a federally qualified health center (FQHC) described a cancer patient who was also a patient at a methadone clinic for his opiate disorder:

> He's having some memory issues probably related to the medication he's taking too much of because he's in pain. I don't think his cancer's causing those problems. But he's not keeping appointments so they don't want to give more meds… And it's a whole big snowball of problems that there's not a good answer to. He didn't have a place to stay, can't go to the hospice place… it's difficult to navigate the the hospital system on your own and having all these appointments… especially when people need pain meds… but then they run out but they can't get a refill because the doctor doesn't want to do it because…it's tightly regulated. And so there's all these constraints around what you can do…people run out of meds because they get stolen. People become targets because they have medications that people want. (Physician at a federally qualified health center (FQHC))

The patient described above is stuck in a vicious cycle: he takes too much medication for his pain, but then has memory problems, which, combined with his homelessness, make keeping doctor's appointments even more difficult. If he doesn't get to his appointment, the doctor doesn't prescribe him more medication, and he ends up being in more pain, at which point he will continue taking too much medication until he exhausts his supply.

A physician further described the necessity of a long-term relationship with a patient in order to feel comfortable prescribing medications, specifically opiates or benzodiazepines.

> People want them and I don't necessarily want to give them. Most of the time… it's not the right medication… It might seem like it's going to help but it causes a lot of problems… I would only do it for someone I knew for a long time; I had tried 10 other things; I trusted that they could do this. (Physician at a federally qualified health center (FQHC))

However, there was not full consensus on the topic. Some of my interviewees expressed frustration in this withholding of opiate prescriptions:

> It's often hard to find providers who are comfortable working with our folks… It shows up particularly around pain management. It feels like there's this weird toggle where everyone's super afraid to prescribe opiates, and then at end of life, opiates are prescribed quite liberally. And for folks who have substance use disorder, it feels like that transition or differential or toggle or whatever you want to call it is even more pronounced. (Social worker at a community based organization)

The controversy of pain management, as well as policies towards substance use, are other barriers that interviewees saw as limiting care seeking. Literature affirms the complicated landscape of pain and symptom control (de Veer et al. 2018). When terminal illnesses were layered upon chronic pain issues, patients were often “afraid of going in because they don't think, for good reason, that their pain will be well managed (Social worker at a community based organization). My interviewees described how some of their clients and patients with chronic pain turned to self-medication with street opiates.

Other patients were wary of the medical system, but also so overwhelmed by their situations, that seeking out care did not make sense to them. The experiences of a man with metastatic cancer who was an alcohol user (mentioned earlier in this chapter) illustrate this:

> He had to leave his last housing because the building got sold and a cascade of things happened. He's…being treated like garbage and having to deal with just a lot of life logistics of trying to get in a shelter and trying to make the flow of his day work. And

> then he has a lot of legal obligations that he has to manage, like registration requirements, probation, classes, and then he's like, I don't have the mental capacity to deal with this on top of all of that, and **they're just going to tell me that there's nothing they can do for me, so why would I bother to put myself through that?** (Social worker at a community based organization)

Literature on this subject supported this idea that individuals experiencing homelessness who use illicit drugs were less likely to receive and/or adhere to treatment (McNeil & Guirguis-Younger 2012). Many end of life care services had zero-tolerance policies towards illicit drug use, which excluded this population (McNeil & Guirguis-Younger 2012). This was not seen in the services which I interviewed, particularly because the selection of these individuals was based on their engagement with the homeless population. However, it is true that medical professionals found it difficult to determine the causes of adverse drug reactions or changes in health status because of unknown illicit drug use (McNeil & Guirguis-Younger 2012). Additionally, in the literature, many providers identified a lack of training in how to support clients with illicit drug use (McNeil & Guirguis-Younger 2012).

V. Lack of knowledge

Many times people experiencing homelessness may not be aware of the options that are available to them, which bars care seeking.

> Part of being homeless and part of how you get to that place is not knowing what you're entitled to, what your rights are, and what you have access to. Part of it is an educational process of letting people know that they do have rights and…to take this hospice benefit that is provided through Medicare or Medicaid. (Chaplain at a hospice center)

Interviewees also attributed survival priorities as a factor that limited people's knowledge on their options of end of life care.

> People that are homeless don't really have any knowledge of what their options are, as far as sort of an end of life plan, or they don't really even think about putting one in place

> because that's not their priority. Their priority is just to try and survive…**They just see what's right in front of them and they don't think about looking into those sorts of options**. (Housing specialist at a federally qualified health center (FQHC))

The emphasis on not knowing what one's options because it is not a priority is a topic which I will investigate in a later chapter. However, it raises important questions about whether this lack of knowledge on end of life plans is because of a different survival priority, or because people were just never afforded an opportunity to engage with a plan. It also lays significant individual responsibility for care seeking upon people experiencing homelessness.

Interviewees also identified a lack of knowledge among providers or people working with homeless populations. This aligns with previous findings which emphasized a lack of recognition among professionals of the need for palliative care (de Veer et al. 2018; Stajduhar et al. 2019). Many unhoused people do not have a recorded medical history and oftentimes professionals, such as social workers, are not trained to recognize medical problems or palliative needs (de Veer et al. 2018).

> A lot of it has to do with structural competence on the part of providers: [they] don't know how to work with people experiencing homelessness, and particularly people who are experiencing homelessness and substance use disorder and end of life…We've had situations where nursing homes won't take people because they have a high level of behavioral health need, even if they also have comorbid… terminal, physical health conditions. **It's often hard to find providers who are comfortable working with our folks**. (Social worker at a community based organization)

Quite frankly, it is disturbing that this interviewee identified comfort level as a major reason that providers do not engage with people experiencing homelessness at end of life. This emphasizes how critical it is that providers engage with this topic of end of life care and are formally educated about how to approach care with this population. A lack of resources for care is one matter, but turning people away from care with the excuse of a lack of knowledge is unacceptable.

Another interviewee described the network of Healthcare for the Homeless clinics, and how they provided clinicians with conferences and newsletters about the specific needs of patients experiencing homelessness. The interviewee contrasted the level of knowledge of these clinicians with the larger provider population:

> I think that people within the system [of Healthcare for the Homeless clinics] are well-informed about these issues of autonomy and the specific needs of homeless patients… **When you go out of that system into the general medical world, it's a roll of the dice.** They're always getting better, but they're not necessarily there to solve that problem so **they're not as interested in solving it**. (Physician at a federally qualified health center (FQHC))

It was fascinating to note that most of the interviewees did not include themselves among the number of people who lacked knowledge about people experiencing homelessness. Perhaps it was because the people who I interviewed were ones who were actively engaged with homeless populations; those who were not engaged would not have responded to my interview requests.

Interviewees also noted that in order to provide higher quality care, providers must be aware of the specific barriers which their patients face. An essential element of this was adjusting expectations:

> We expect people to do certain things that they just either can't do because they don't have the resources [and]…people have different priorities based on what their life circumstances are…These [individuals experiencing homelessness] are people who are not functioning particularly well in society because they don't have what we could call adult living skills, like the skills that you have, that I have, to show up to work every day at the right time. Remember to pay all your bills, keeping your appointments, juggling lots of different responsibilities. And a lot of people don't have those skills for various reasons. So just the idea of having an appointment that you're going to put it in your phone and put an alarm and alert seems obvious to many, but it's not. (Physician at federally qualified health center (FQHC))

Studies affirm this observation that health care providers often perceived social care needs as outside of their expertise and practice (Stajduhar et al. 2019). Yet, it is these everyday requirements for survival that deeply influence the capacity for individuals to seek out services and have their palliative care needs met (Stajduhar et al. 2019). Literature also described other settings where much of the burden of care for homeless people at the end of their lives fell on hostel staff, despite them having little to no medical training or experience (Shulman et al. 2017). Hostel staff described experiences of guilt, trauma, stress, failure, and devastation as they provided care for homeless individuals at the end of their lives (Hudson et al. 2016). Many simply did not have the training to provide appropriate palliative care, and thus found it difficult to meet the needs of their clients (Hudson et al. 2016; Stajduhar et al. 2019).

Interviewees also cited the importance of truly engaging with the population in order to understand their needs:

> Unless you're out there working with the folks, it's really hard to understand what these folks are living in, what they're going through…they're in survival mode all day long to just try to get through the day. When they get into facilities, that stuff just doesn't dissipate. It's still there and they're still carrying a lot of weight. (Director of outreach and communications at a church)

The general inexperience of professionals working with individuals with “challenging” behaviors often led to a perceived prejudice and lack of compassion towards homeless people, which in turn limited how much homeless individuals wanted to engage with the medical care system (Shulman et al. 2017; Klop et al. 2018). As described above, it is also difficult for professionals working with individuals experiencing homelessness to understand the particular barriers to care if they have limited experience confronting these issues or lack long-term relationships with people experiencing homelessness (Krakowsky et al. 2013).

Some interviewees recognized their own lack of knowledge and were honest about where they stood:

> The Health Care for the Homeless organization….have a conference every year. And I do know that end of life care is one of their initiatives. I guess short of going to one of the lectures there and looking at some of their online resources, I can't say I've had any specific training or information that was provided on that topic alone. (Psychiatrist at a behavioral health center and community based organization)

This highlights that the resources which the Health Care for the Homeless organization provides are essential tools, and perhaps also critical in helping providers to understand the extent of knowledge which they do not know. The question then is how persisting gaps in knowledge can be met and how more formal training protocols can be integrated into the clinics themselves to operationalize material learned in lectures and conferences.

Finally, interviewees also identified ignorance of the general public as a barrier. A CEO of a social services organization noted that hospice has been in the U.S. for over 40 years, but that there is still a lack of knowledge about the idea of hospice, end of life, and what it means to assist people to have a good death. Other interviewees highlighted similar observations:

> I'm often taken aback by people's lack of knowledge about the end of life; they haven't seen what it looks like to be dying of a variety of conditions, and so they're generally unprepared to meet people's needs or they don't have a sense of how the disease trajectory might go. I think that that lack of education generally makes it harder for people to make the right choices for themselves and for their loved ones. (Associate professor at the School of Public Health)

Others noted a huge separation in knowledge between those doing the work with people experiencing homelessness and the general public:

> I don't think the general public is intimately aware of the issue [unhoused elderly] as much as we are, that are…doing the work and hearing about the work all the time. There's a huge discrepancy there. I don't think it's really portrayed in the media enough. There's just a large ignorance of the issue in terms of the people who aren't doing the work. (Housing specialist at a federally qualified health center (FQHC))

This ignorance will persist if the stories and struggles of people experiencing homelessness are not made more visible. The lack of knowledge on this population, particularly among professionals, is not just a result of personal ignorance, but a result of the way in which narratives about people experiencing homelessness work to obscure their needs. As this chapter has attempted to show, the end of life care landscape is intensely complicated for people experiencing homelessness. Barriers to care and the challenges of providing this care compound each other and work to exclude people from care. Many of these barriers tie into the ways in which individuals experiencing homelessness are rendered invisible by the medical system and bureaucracy. This is evidenced by the lack of public data on the number of people experiencing homelessness who are elderly or who have terminal illnesses, and by insurance policies and shelter rules which block people from care. The "work around" and the "fighting upstream" which service providers must do to try and provide care highlights that the U.S. government is actively practicing a policy of "letting die."

As Hojdestrand described in her ethnography of St. Petersburg, individuals experiencing homelessness felt a deep sense of rejection and worthlessness: "I'm not needed by anybody – as if I'm not *human*!" (Höjdestrand 2009, 2). Is this the narrative that we want to perpetuate? I am encouraged by the amount of data on barriers to end of life care for people experiencing homelessness that I was able to collect; it means that the professionals working with this population are aware of the challenges which they face, that they are listening to their needs and frustrations and life stories. That in itself is heartening, but this call also extends beyond these service providers. It is a call to you and to me to *care*, to validate the humanness of people experiencing homelessness. It is a call to ensure that their stories are not swallowed up, and that each and every one of these individuals knows that they are valued and seen.

Chapter 2: “It's not really a system per se. It's just a network of connections”

In this chapter, I will explore the network of resources among people providing end of life care to individuals experiencing homelessness. This chapter aims to highlight what this network of resources looks like, as well as its limitations and strengths.

I. Networks of resources

The people who I interviewed often described the end of life care landscape for people experiencing homelessness as an informal sort of network, often built on personal relationships between providers, social workers, or community based organizations. Much of this stemmed from an acknowledgement that each organization alone could not provide holistic care for individuals, and thus, it was necessary to seek other resources to meet needs. For example, a social worker at a hospice center emphasized how they were “an intermittent service for someone who is cared for primarily by someone else” and that required reaching out to other organizations to provide more ongoing care. A director of outreach and communications at a church echoed a similar idea, emphasizing that their church space was a “quick stopgap emergency bandaid” where people could come to be referred to shelters or community based organizations with direct connections to hospitals or rehabilitation centers. A study by McNeil et al. (2012) emphasized the importance of “third-party advocates” like this who could strengthen the partnership between community agencies who engage homeless populations and the end of life care system.

A social worker at a community based organization went on to describe the networking process with healthcare providers:

> When I started, we didn't have any connections with healthcare providers. And it just emerged organically. We just started working with providers… [and] the medical school and now the great thing is…the students…become residents and then they become attendings. And so we've sort of been **organically growing our network**. (Social worker at a community based organization)

> Most of it is pretty informal…. We work with a lot of medical providers at Lifespan but not because we have a contract with them. Just because we see the same people on the population and individual level and so we form connections and I will reach out to doctors that I know and say, 'Hey, do you have your panel for this patient?' And they'll reach out to us and say, 'Hey, I haven't seen so and so. Can you keep an eye out?' or 'hey, you know so and so? They're experiencing homelessness. Can you connect with them?' So **it's all very organic**, which sometimes can be challenging because we don't have health appointments. I can't see Epic, I can't see the medical record like the EMR… so some of that stuff that's hard. (Social worker at a community based organization)

The network which this social worker described was one built on person-to-person relationships, rather than collaborations between organizations. The investment of these service providers often gave rise to more personalized care, as well as creating a community of resources. However, this introduces the problem of sustainability because such in-depth care for each individual means that this level of care cannot be provided to all patients. It also depends heavily on service providers themselves and their drives to provide this care. This again returns to a fear of burnout among service providers as they struggle to bear the huge emotional burdens of end of life care (Stajduhar et al. 2019; Hudson et al. 2017).

For organizations that had different branches (of social work, healthcare providers, chaplain, etc.), they identified how they created informal networks of resources and protocols *within* their organization to address the needs of clients. A chaplain at a hospice center described an informal funding system:

> I would say that we don't have a proper infrastructure, that we don't have a protocol in place…We at [the hospice center] have a… compassion fund. And this compassion fund is funded through employees…One branch is for staff members who… can apply to this fund and get support. But our social workers can also apply to this fund on behalf of our

> patients and get things from air conditioners to maybe hotel vouchers. Food presents for your family at the holidays. Turkey at Thanksgiving. A tank of gas…a gift card to Stop and Shop, things like that. (Chaplain at a hospice center)

A housing specialist at a federally qualified health center (FQHC) described varying practices for care coordination of patients, sometimes being as informal as a message sent in the morning "just to make sure that we're pretty much up to date in terms of who's doing what":

> We do our best with the limited resources that we have but I can speak to our Health Center in that we have a lot of buy-in from our providers, who are super invested in the homelessness issue and how it impacts all people across the lifespan…. we just all work together and get super creative in how we can best meet the needs of people…internally, we really have a lot of compassionate people, which is helpful. (Housing specialist at a federally qualified health center (FQHC))

Interestingly, both interviewees highlighted the centrality of compassion to these informal networks; compassion was generative of creative and flexible solutions because people were willing to be generous with their money, time, and hard work.

Interviewees also provided examples of more structured relationships. Some identified how this was centered around care coordination built into their organization's protocol. For example, a housing specialist at a federally qualified health center (FQHC) described their role alongside healthcare providers in assisting patients with advocacy, budgeting, and housing support. A psychiatrist at a behavioral health center and community based organization also identified the care coordination which case managers and registered nurses did for their patients.

Other interviewees spoke about the structured relationships *between* organizations. For a hospice center, this was a relationship between the hospice center and local hospitals, clinics, shelters, and cancer centers. For a FQHC, this came in the form of regular communication with health insurance companies which provided coverage for their patients:

> Most of our patients have Neighborhood [Health Plan] and it's a Medicaid product, not commercial. We meet with them monthly…. There's two more [health insurance

> companies] that have Medicaid products in RI. We meet with them quarterly because we don't have as many patients. In the interim between those meetings, we send encrypted emails about the patients if we need to. We might not be able to reach a patient. For example, if we're identifying that they might be in crisis or that they have chronic conditions that need follow up and they're not following up, and maybe we have a wrong number or something, we'll reach out…because they can see on their end if the patient has been seen anywhere else and that's how we can track them down sometimes. (Director of integrated care management at a federally qualified health center (FQHC))

A social worker at a community based organization also spoke about a more formal relationship with providers and their organization:

> One of the formal things we do have…is we do buy out doctor's time. We have three doctors that come out and outreach with us…so they can see folks on location [or] they can self-refer, basically bring people onto their own panels. (Social worker at a community based organization)

Even here, within these formalized relationships, we can see the important role of flexibility and spontaneity. Patients experiencing homelessness often required an extra layer of care, which called for both sides of these partnerships to engage to a degree beyond the average patient.

Workers at a healthcare governmental agency described themselves as a hub of federal dollars for the development of programs, which organizations could access through formalized proposal requests. Collaborations with other divisions of the governmental organization and community based organizations led to the creation of projects such as a medical respite pilot and the 24 hour warming station. Both of these initiatives provide services for people experiencing homelessness and offer a point of contact for medical providers. Overall, the collaborative effort of various divisions of the governmental organization and weekly meetings were essential to develop non-siloed plans to serve the homeless population. Having the power of being a larger regulatory body also meant that this governmental organization fielded complaints and acted as a formal center of communication with provider boards, hospitals, and community advocates. They also enacted training and learning communities on a state level.

Whether formal or informal networks, a central theme was collaboration and regular communication. As a chaplain at a hospice center described, these networks of care were like a flower with the patient at the center:

> [There are] all the different petals that that person already has around them, such as their family, friends, their residential program staff, the residential program nurse, social worker, and on and on. And then I put hospice as a stem of the flower supporting that whole constellation…**We're not coming in to pluck the flower and destroy it. We're there to really support**. (Chaplain at a hospice center)

II. *The importance of an individualized approach to care*

The flexibility of these networks of resources reflected the range of trajectories at end of life for patients experiencing homelessness. As a director of integrated care management at a federally qualified health center (FQHC) stated, "It's very person-specific, because every situation is different." Another interviewee detailed this range of trajectories:

> We certainly had people come into PSH [permanent supportive housing] and then get homecare services and die in their own apartments, which frankly, feels like in many cases, the best case scenario... We also have people who die outside, who never [get] connected at all, kind of another extreme. We certainly found people dead of a cascade of health conditions….And then other people will connect them with nursing homes at the end of life, and they'll die in nursing homes. (Social worker at a community based organization)

Another interviewee described the complexity of end of life care, but also the ways in which different organizations complemented each other to provide necessary care:

> We're rarely the only support that people have got. If they're homeless, they may be connected with… another program doing outreach and providing services… they're probably connected with one of the hospitals in the area. So we're coming in as this kind of additional layer of support…it's really a **kaleidoscope with lots of moving parts and pieces**. (Chaplain at a hospice center)

This shared goal does not necessarily mean that the routes towards providing end of life care for people experiencing homelessness were always aligned. As an office manager at a healthcare governmental organization described, “there’s riffs in the process about how we're going to get there…the angle aligns, but sometimes the communication along the way needs to be worked through to figure out what is the best pathway.”

A central theme which many organizations identified was that of “meeting people wherever they are at.” In some cases, this meant going to whatever location people identified as being “home”:

> …a house, an apartment, a residential program for somebody with disabilities, a temporary shelter, a tent under a bridge…We're flexible. We wouldn't refuse to serve somebody because they lived in a particular spot, but we'd find ways to provide care that was safe for everybody and effective. (Chaplain at a hospice center)

This also meant being aware of the constraints which particular patients faced, especially in getting to medical appointments:

> We have some elderly patients, who recently have become homeless that are living in their vehicle and if that's the case, some folks can drive to the clinic to get care. But some also use their gas or heat, so they can't drive because they can't afford the gas to both use for their heat and to get to the clinic. So we would get creative and meet them in the community, figuring out like, ‘Okay, can we Uber you here to the clinic, even though you have a vehicle?’ (Director of integrated care management at a federally qualified health center (FQHC))

This focus of “meeting people wherever they are at” requires a great deal of flexibility. Interestingly, the majority of the discussion on this theme was done by individuals who worked at nonprofit organizations. Interviewees explicitly identified a separation between nonprofit and for-profit agencies, wherein non-profit organizations had a “different level of responsibility” and would not turn people away because of a lack of financial resources (Chaplain at a hospice center). This leads us to the question of whether the kind of flexibility required for this work is a luxury that for-profit organizations simply cannot afford. But this then becomes reminiscent of the idea of profitability valued over human life, described in the previous chapter. Ethically, this cannot hold up as an excuse.

Another larger question is that of replicability and feasibility. As a director at a FQHC stated, this kind of care is outside the "normal scope of practice…it's a whatever's necessary type of thing." These creative practices occur because passionate individuals are committed, at an organizational and personal level, to provide effective care to their patients regardless of living situation. How can this be replicated on a larger scale and be sustained long term?

III. Limitations to networks of resources

Interviewees were practical in their descriptions of these informal networks of resources. Though they emphasized the strengths of these networks, they also acknowledged their limitations, as well as the ways in which the general structure of care or the lack of resources prevented them from fully addressing gaps in care. A social worker at a community based organization described how informal networks allowed their clients' wishes to shape the type of options which they pursued:

> I actually really prefer it [informal networks of providers] because it lets me talk with the individual and say, 'what's important to you in a provider? What's important to you in the care that you receive?' And then **be able to select from a menu of options instead of having a default where I have to refer to PCHC** because we have a contract, whether or not I think PCHC is the best fit for this particular patient. (Social worker at a community based organization)

Even though they highlighted this strength, the social worker also went on to say, “The hard part is thinking about trying to scale it up. **Because it's not really a system per se. It's just a network of connections.**” (Social worker at a community based organization)

Other interviewees expressed frustration with the limitations from the lack of a formalized structure or protocol.

> But the protocol for people who are homeless who are on hospice is not well established here…There's not a space for them to die with dignity unless a hospital is willing to keep them and nine times out of ten, a hospital will not be willing to keep them because they're homeless. They'll keep them if it's medically necessary but they won't keep them because they don't have a place to go. (Chaplain at a hospice center)

Others described difficulties with communication:

> Yeah, that's true for hospital case management staff. I'm not going to lie to you, we have a hard time getting in touch with them to coordinate on our patients so I don't know if you would be successful in reaching them. (Director of integrated care management at a federally qualified health center (FQHC))

Part of this difficulty in communication was as a result of the siloing of substance use services and housing services:

> In Rhode Island it is a little siloed with housing services and then substance use services is this other kind of pillar… I do think that's improving, but often in policy and with big meetings that get scheduled…the housing folks aren't always invited to those meetings. And those aren't things that I think can be separated. They are very much intersecting for a lot of people…. It seems like there's been more and more dialogue [between community organizations] with increasing overdose rates and people dealing with housing instability. At the community level, it's there, but it's making sure at the state and structural levels that these things are discussed across organizations, not just with some organizations. (Associate professor at the School of Public Health)

Shulman et al. (2017) echoes this idea of how a fragmentation of health, housing, and social services prevents a person-centered approach to care. A siloing of services means that much of the burden then falls upon individuals experiencing homelessness to navigate multiple different organizations, all while they become increasingly more exhausted and sick (Stajduhar et al. 2019). This interviewee also raises an important point about the scales of change. While they noted communication growing between organizations on the community level, there was still a need for communication at the state level.

Nearly all interviewees expressed feeling helplessness and frustration in the face of the lack of resources available to this population of homeless individuals.

> It's tough because there's not a default or pre-made option for that community of folks. And so it's often feeling like you're kind of **trying to wedge a square peg into a round hole** in terms of what's available within this constellation of resources. (Social worker at a community based organization)
>
> The lack of resources is just extremely **infuriating**. To be the messenger that, 'hey, I know this really sucks and like you should not be having to deal with this, but there's really nothing for you right now. Any options may take six months.' (Director of integrated care management at a federally qualified health center (FQHC))
>
> **It feels frustrating because there are so few answers, good answers**…there's all of this unmet need. So that feels frustrating because when you want to help somebody, whether it's with a paper or life issue, when you've got nothing to offer them, **it really feels awful**. (Social worker at a hospice center)

All of this is in spite of the best efforts of these service providers. They have not given up trying to fight for their patients and create flexible plans of care, but many times, there is little that they can do.

> I can certainly say that people who advocate for these populations generally are trying to be helpful and to coordinate services, but… sometimes I **feel like we go in circles just looking for resources and trying to find something that's going to fit a need**. And then we all just kind of talk about how much unmet need there is…we don't get very far. (Social worker at a hospice center)

Again, this ties back to an earlier point about how hospital procedures and bureaucracies of the healthcare system shape dying, and individuals, such as providers, social workers, chaplains, and patients, can only act within existing systems of classification (Kaufman 2005). In many ways, the limitations to the agency of these service providers is quite clear, given the realities of time, money, and resources. Kaufman (2005) described how the hospital’s primary task is to “move things along,” though hospital staff will rarely use this phrase; for this population of people experiencing homelessness who are involved with the medical system, it feels like quite the opposite. It is stagnation of care or a discontinuation of care.

Collectively, my interviewees identified a significant breadth of available resources in the community, as well as key individuals involved in the provision of care. It is worth considering what different interviewees pointed out as subjects that they were not familiar with, and the extent that some went to emphasize that they were not familiar with resources available to this community. For a chaplain at a hospice center, this was policy and the healthcare system. Others emphasized a much more broad lack of knowledge about end of life care:

> I wouldn't say it's often, but we've had some people who've gotten older who have transitioned to assisted living, some of whom have been homeless. Charles Gate is one of the facilities that has provided care to folks that have been taken off the street into assisted living. I think there's others as well. I'm just not familiar with those, as much. So if folks have the insurance coverage, Medicaid and Medicare, they are able to make that transition. **I've never had a conversation with a homeless person about end of life and end of life care**. (Director at a community based organization)
>
> **I don't think I have a lot of information about end of life care**… I think that you have to be plugged into some agency or hospital or something…for example, I know there's an inpatient hospice unit on North Main. I don't know how long people can stay there… sometimes people go there for a week or two to determine their level of need and then hospice care would get delivered in the community….I don't actually know…if someone's literally living in a shelter, whether they could get hospice care. I doubt it but I don't know…I'm not sure. I doubt it. I just don't know. It obviously wouldn't be preferred, but I don't know. Do you know? (Physician at a federally qualified health center (FQHC))

Although some interviewees insisted that they knew very little about the topic, they still had at least some degree of familiarity with the end of life care landscape. For example, with both excerpts above, each interviewee identified at least one end of life location and certain key elements involved with access criteria for people experiencing homelessness.

It was particularly interesting to survey what workers at a healthcare governmental organization identified as what they were familiar with on this topic, especially as they were from a division of the organization dedicated to housing. An office manager at a healthcare governmental organization had described the Long Term Services and Support (LTSS), 24 hour warming station, and medical respite that their governmental organization directed. However, in response to the question, “could you tell me generally about the end of life care options open to the homeless populations?”, they responded as follows:

> I don't think I can comment anymore on what other options we have for resources for end of life care besides that connection to hospice resources in our various programs. (Office manager at a healthcare governmental organization)

A director at the same governmental organization had a fairly clear stance on how often this population ended up in nursing home level of care:

> It's a little bit of an interesting population that you're focusing on because **I'm not sure how many folks who end up with those severe health needs and are unsheltered don't in some way, shape or form end in some sort of nursing home level of care**…I just actually don't know the total number or quantity [of critically ill or elderly people experiencing homelessness]…However, most often I think we are working on trying to find out how we make those connection points with hospice care. Is it simply residential? Is it in other community based settings…? Does hospice exist…? These are questions we're looking for answers about now. (Director at a healthcare governmental organization)

But later, when asked how often hospice services were recommended or obtained, this same director stated:

> **I don't happen to know the answer for that**. I'm not sure how much that ends up from a nursing perspective, or a shelter perspective. (Director at a healthcare governmental organization)

It is difficult to fully grasp the stance of this director, but it is clear that they are not fully aware of the extent to which they do not know, which is rather concerning, given that this director is in a role of power that directly affects the types of projects created and the type of research conducted on housing.

As a whole, it is evident that there is a very real, informal network of individuals providing end of life care to people experiencing homelessness. This network is built upon informal, personal relationships between workers, as well as more structured, organization-wide partnerships. Interviewees also pointed out the critical role of flexibility and “meeting people where they are at” in the approach to providing end of life care. This differs from other literature, which advocated for more formal partnerships between health and social services agencies and the end of life care system (McNeil et al. 2012). However, my interviewees were honest about the limitations to these informal networks of resources, as well as their own limits in knowledge. The trends that emerged through these interviewees parallel other studies which uncovered a great need for better communication and cooperation between agencies (Davis-Berman 2016).

Other studies also found that knowledge about hospice and end of life care for people experiencing homelessness was very limited, with few respondents being aware of whether patients experiencing homelessness accessed hospice services (Davis-Berman 2016). This differed from the responses of my interviewees, who often had personal experience in working with people experiencing homelessness at end of life. Again, it is important to emphasize that my interviewees may not be representative of the broader spectrum of workers. The fact that they were willing to speak to me about this topic indicates a certain interest, passion, and knowledge about the subject of end of life care for people experiencing homelessness. As one interviewee described in an earlier chapter, outside of this specific network of interest, “when you go out of that system into the general medical world, it's a roll of the dice…they're not necessarily there to solve that problem [of end of life care for people experiencing homelessness], so they're not as interested in solving it" (Physician at federally qualified health center (FQHC)). Though this example specifically pertains to healthcare providers, we can extend it to include others involved in end of life care work. This separation between providers who care and those who do not is critical to consider as we think about ways in which these informal networks of connection can be extended to a larger scale.

Additionally, while it is important to note the strengths and the value of these more informal relationships, it is also worth questioning their sustainability and the ways in which they might act as stopgaps or band aid solutions to larger solutions. Though these service providers may attempt to create systems that differ from existing and broken systems, we cannot deny the fact that they are still operating within these broken frameworks. This is not to say that these informal networks do not function, but it is something to consider, about the ways that these relationships might reduce a recognition of the need for larger scale change surrounding end of life care for people experiencing homelessness. These hard-won networks might give the state and government reason to feel there is less urgency to get involved. Yet, at the same time, if these individuals do not build these informal networks and fight for the rights of their patients and clients experiencing homelessness, who else will?

Chapter 3: Friendships, Not Burdens

I. *Relationships at end of life*

While the previous chapter explored the network of resources between service providers and organizations, this chapter will explore the importance of relationships between these professionals and people experiencing homelessness at end of life. Literature on this topic emphasizes how patients experiencing homelessness often lack a support network at end of life, which amplifies the importance of these relationships with service providers (de Veer et al. 2018). My interviewees identified a lack of family support as a critical missing element.

> In the housed population, we see hospice being very successful with supporting families and supporting the patient to live in their home with their family and spend their last days. Our folks that are unhoused in most cases have neither of those things. Have neither the house nor the family to be the primary caregiver and to be that support. **So that hospice model of supporting a family at home, it just really doesn't fit with that population**. So it seems like the default then is for folks to be inpatients in the hospital and living their last days in an acute setting. (CEO of a social services organization)

These responses all highlight the centrality of family members for the provision of caregiving during end of life care, which is also evident in other literature on the topic (Henry et al. 2017). It also returns to an earlier theme in Chapter 1 of the barriers that exist in the very structures which make up end of life care. As Stajduhar et al. (2019) describes, the design of the end of life care system is a "one-size fits all" or "blanket" policy that does not recognize diverse life experiences. It does not ask *"who* needs *what kinds* of support," and it does not account for ideas of what home and family mean to different people (Stajduhar et al. 2019).

What does policy say that home is? What does it define family as? How does this isolate particular vulnerable groups of people? These are questions that need to be asked. Yet, the United States lacks a systematic approach to address "unbefriendedness" (Health Care for the

Homeless Clinicians' Network 2018). Quite obviously, it is difficult to systematize the formation of friendships or consistent, long-lasting support networks of care; so much of it depends on individual effort, time, and willingness. Yet something must be done, because this "unbefriendedness" and lack of a support network has major implications for people experiencing homelessness at end of life. For example, many patients experiencing homelessness are less able to appoint a health care proxy to assist in medical decision making, which is critical if they are incapacitated towards end of life (Health Care for the Homeless Clinicians' Network 2018).

A social worker at a hospice center talked about how people they worked with have often "burn[ed] their bridges" with family or been "too complicated" for family members to continue to support. Many other interviewees also cited strained family relationships as a reason for the lack of familial support among their patients experiencing homelessness.

> The circumstances that may lead to homelessness or housing insecurity include things like substance use or personality disorders that will often come with difficult family relationships. There were certainly many cases of us [at the ER] calling family and people not wanting to come in…at some point, I think many of them would realize that this person was dying and it was their last chance to say goodbye, but [it] often would appear to not have been a straightforward, 'of course, I'm going to be there for this family member who's terminally ill.' It was difficult. (Associate professor at the School of Public Health)

While these quotes seem to point to personal problems among individuals experiencing homelessness as reasons why family strain occurs, a study conducted by Song et al. (2007) took a different angle. It examined how individuals experiencing homelessness in Minnesota felt about death and dying and found that emotional detachment and isolation from family was often a coping mechanism, as most individuals had significant personal experience with loss early in their lives. These individuals experiencing homelessness expressed a great fear of being a burden to others and for this reason, they often distanced themselves from their families (Song et al. 2007).

In some cases, family was willing to reenter a person's life, but this did not necessarily align with the patient's desires:

> We had one man come in from a shelter and…they anticipated that he would die relatively quickly, and he didn't. And so then it was the challenge of, well, we can send you to a shelter…[or] do you want to go and live with your family in Pennsylvania? And **usually people aren't interested in even attempting to contact [their families]**...…We talked very seriously about him going back to his shelter, which I really didn't want him to do… He had had a couple of conversations with his sister in Pennsylvania and it seemed like they were receptive to him going back. He didn't even want any part of it. (Social worker at a hospice center)

On the other hand, a different interviewee spoke about a time when he was a part of the process of mending a family relationship, based on a client's expressed desire:

> It was somebody who was no longer really in close contact with her children, and just going through the decision process about reaching out or not reaching out and then how to go about doing that…For this individual, there were friends and people that certainly were supportive, but she wasn't connected with her kids anymore, and really wanted to try to make that happen. She ultimately did that with assistance from staff…just wanting those reconnections. (Psychiatrist at a behavioral health center and community based organization)

These conversations illustrated the complexities of the relationship between people experiencing homelessness and their families, and the ways in which family relationships are simultaneously part of the barriers to end of life care *and* the solution.

II. Trust and continuity of care

The lack of family support networks, which are critical for navigation of the end of life care system, mean that professionals working with this population of people must often assume the role of caregivers. They must go beyond a professional relationship and take on a more time-intensive, personal relationship with their patients. Literature describes a similar phenomenon: as hospice care workers attempt to balance people's comfort and dignity in ways that step beyond their formal job descriptions, they end up facing significant emotional stress (Stajduhar et al. 2020). All this occurs while they receive little recognition for the additional services they provide and are not given access to resources or support to help them with fulfilling these roles (Stajduhar et al. 2020). Another study on Swedish support homes for people experiencing homelessness described a similar challenge, wherein many of the patients lacked relationships with family members, and so service providers often took on these roles through the formation of close and trustful relationships (Hakanson et al. 2016). This came with its own complexity, in finding the balance between closeness and family-like relationships, and a professional distance (Hakanson et al. 2016). As a chaplain at a hospice center described:

> We have to be conscious of our own feelings that may come up, because we can't fix everything. We can't bring them all into our home. We can't provide shelter for all of them. We can't provide clothing or food for all of them. And so we have to be really careful with our boundaries as care providers, which is tough. (Chaplain at a hospice center)

Another interviewee also described the particular type of grief that came with caring for this kind of population, in balancing a deep personal relationship with his patients and his professionalism:

> We can kind of get stuck when we don't allow ourselves to grieve in a personal way. What can get in the way is if we feel responsible, we feel like we could have done something, we should have done something. We didn't really give ourselves permission to experience it in the way that we would otherwise, so I think…realizing that this was someone who I'm going to miss, who I was connected to. And it doesn't make it easy… it makes it healthier, I suppose, to kind of go about it that way, but it's always quite difficult. (Psychiatrist at a behavioral health center and community based organization)

This interviewee faces a complicated kind of grief, being someone who cared for a person as a patient, but also as a friend. In occupying this space, they also bear responsibility that is professional and personal, which can create great emotional burden.

And yet, despite these additional burdens, my interviewees spoke about a commitment to building real relationships with their patients or clients. A social worker at a community based organization described how having a long-lasting relationship with a client meant that "he trusts my judgment and I'll be real with him" in recommendations. Another interviewee explored how community based medicine helped build up trust:

> There are always some providers that do more community based medicine and outreach based medicine and go to where people are. And…people view them much differently than people who only are in the clinic. There's a lot of trust because people are taking the time to build that trust with folks going to encampments or working in community clinics that are much more low barrier. (Qualitative researcher)

This aligns with other literature on the topic which emphasizes how trust built up between homeless populations and health and social service agencies help provide access to various services (McNeil et al. 2012). My interviewees also explored the ways in which they maintained continuity of care to build trusting relationships with people experiencing homelessness.

> I do see folks in an ongoing way, in the same way that I would at another outpatient clinic, sort of seeing people every month or every two months, depending on the clinical need. But then doing outreach, it's definitely interfacing with new people each week or folks I have seen before. Rhode Island is a small place, so it has a lot of familiar faces and some of the same folks…So I would say we do regularly see new people, but it is a lot of the same folks. (Psychiatrist at a behavioral health center and community based organization)

A housing specialist at a FQHC also highlighted the ways in which people from different aspects of a person's care can collaborate to provide this continuity of care.

> It was a no show [for an appointment] and then I tried calling her. She didn't answer…She's also involved with…a health worker. I messaged that person this morning, ‘Hey, did you hear from such and such?’ and she's like, ‘I spoke with her this morning. She said she thought she heard a knock but she said was sleeping.’.... But it was just something to let us know she's still around, she's alive. It's just working as a team….This patient just needs a lot of baby steps along the way and whether it was just showing up anyways if she didn't answer my phone call, we would still just show up. She put a lot of trust in us because we've been working with her along the way and showing her that we were following through and we were there for her. That's her willingness right now to be so open to the work that [the FQHC] has been providing. (Housing specialist at a federally qualified health center (FQHC))

Just as this housing specialist described, it is often small steps of outreach that build trust and relationships. Familiarity with a patient means being able to detect needs before they pass the point of urgency.

For folks working at a federally qualified health center, some of the continuity of care was built into the structure of the organization, through housing specialists who provided case work services to patients.

> We can work with the patient for 24 months…it can be consecutive, or it can be broken up however. So even if somebody gets housed, let's say after six months, we would still want to work with them for as long as it takes until we can agree with the patient like, ‘okay, you're stable. You don't need us anymore.’ Even though they're housed, we still want to work with them to make sure that they're able to maintain their rent; they know who they're paying rent to. We've seen them do it independently a few times… They know the rules of the housing authority, they're abiding by them. They're not having other people stay with them. They're not being taken advantage of or exploited, especially if they're elderly…We pretty much all work with people for a length of time. It's never just a one off….Typically folks need more longevity with the services. (Director of integrated care management at a federally qualified health center (FQHC))

For others, continuity of care was a role which they put upon themselves. A director of outreach and communications at a church described taking people directly to the hospital in emergency situations:

> I'll…be a voice and an advocate to help them try to get the proper care that they need…I do make sure that I go in to just figure out who's taking care of our folks and just have a brief conversation about where they're coming from, what I've gone through with them, just so they understand a little bit of the picture. But when I leave and walk out the door, there's obviously not always an advocate there to speak on their behalf…They always get the proper medicines but food and stuff that is supposed to be provided, it doesn't always seem like that happens. I try to interject and have conversations with staff there to let them know what's happening. So it's really just being an intermediary between patient and staff. (Director of outreach and communications at a church)

This interviewee raised concern about the importance of advocacy, and the power of being a witness to make sure that proper care was received. They also used the term "intermediary" to describe the role which they played between patient and hospital staff. This is the role that family members might be expected to play, which again emphasizes how important it is that service providers invested in these peoples' lives step in to fill this role.

And again, to return to an earlier theme of flexibility, my interviewees illustrated how each patient had very different needs for follow up, and this required service providers to enact continuity of care accordingly. A housing specialist at a FQHC described this range of patients' needs:

> She's recently housed and I would call for a quick follow up phone call like, 'hey, how are you doing today?'... She doesn't really have too much support so even if it's just a simple phone call on a daily basis, there's so much that we can pick up on that might be needed. So **I would have that one patient that I would call every day and then I would have some that I would see on a weekly basis. It really depends on their level of needs**, and some are a little bit more self-sufficient than others. (Housing specialist at a federally qualified health center (FQHC))

Interviewees also talked about how this continuity in care allowed them to see the progress which their clients made, and allowed them to be a part of celebrating steps forward:

> I'm big on celebrating the small wins. So whether that person starts regularly showing up for their appointments, or is able to do something or call a Housing Authority independently one time, that's something that we really try to encourage and to celebrate

> because a lot of these people, without our assistance, might not even be able to get where they're at…That's still huge because without all the work that you put in before that, that would have never happened in the first place. (Housing specialist at a federally qualified health center (FQHC))

III. "Seeing" someone

Much of the literature on this topic talks about caregiving for people experiencing homelessness at end of life as a burden, but none of my interviewees used burden as a description for their work. Most of them spoke about the responsibility to make their patients feel seen, and even about the friendships which they had with individuals. Theirs was a narrative about celebrating victories together and living life alongside each other.

The language surrounding relationships with clients and patients experiencing homelessness was that of "seeing" someone and understanding their story. This is a particularly interesting trend, given the ways that structures and policies work to make people experiencing homelessness invisible at end of life, as explored in the first chapter of this thesis.

One chaplain described the privilege of having an official badge and the role of a doctor, social worker, or chaplain:

> It gives me access to people and creates immediate connection in a way where I don't have to spend years trying to create that. The door is open for me and I have to treat that with such respect and reverence because this person's about to share some really intimate and vulnerable information with me and I have to make sure that I hold that really close to my heart and that **I acknowledge to them what a privilege it is to hear what they have to say.** (Chaplain at a hospice center)

A lot of "seeing" someone involved countering stigma which patients faced and discussing the importance of dignity. The conversations about these topics were some of the most uplifting parts of my interviews, and I include these longer quotes to preserve the spirit of what each of these individuals had to say:

> Everyone has their own bias about the homeless population…I used to work in a hospital, providing psychiatric treatment…We size people up the second we see them. They come in with a bag full of things…their shoes are ripped or their pants are hanging at their waistline, or they look like they haven't bathed in a while, we immediately make judgments about them. And it's our responsibility to pause and say, 'Okay, this is a person, you have no idea what their story is.' And part of our responsibility is to understand their story. I think that part of the hospice philosophy is to really, really get to know people and understand them as human beings, but really see them. **At the end of life…most people just want to be seen. They just want to be heard. They don't want to be forgotten**…We do our best as chaplains and social workers to make sure that….we see them with loving eyes and we see them with compassion and we see them with all that they have to offer in the world. Even if they're on their deathbed, they're still providing a source of light and a source of hope to the people who are serving them. You just never know. It takes such emotional intelligence and awareness and also faith and commitment to humanity to make sure that you approach people with a gentleness and kindness that I don't think we always do. (Chaplain at a hospice center)

> There's such a stigma with people who are homeless….**Part of our job is to ask the right questions and to give people a team who are going to care for them and nurture them as if they were a beloved brother, a beloved mom, a beloved grandparent and to treat them with the same respect that we would any other human being that we would encounter.** But it's tough. It's very tough. We're human beings also providing that care and so we have to be really conscious of our own biases. (Chaplain at a hospice center)

> People say to me, how can you work with patients who are homeless and everyone's got depression or drinking? It's what I'm interested in so it doesn't feel difficult in that regard….The fact that I'm interested means that I'm going to listen more and ask more questions than the average doctor seeing that patient…**Those patients, especially homeless patients, don't get as much attention because people are not interested in them, which is terrible. Just the fact that I'm asking these questions and I'm interested, those patients therefore felt seen**, hopefully. That creates a better relationship. That's something that everybody should have in their life, that they feel seen. So it's a positive feedback loop. I'm interested, so I talk and listen, taking longer than other people might; therefore… something positive happens and then they [the patient] come back. (Physician at a federally qualified health center (FQHC))

This honesty was refreshing, that these individuals were trying to respect and treat their patients with dignity, but also acknowledged the ways in which their own biases and judgements got in the way. These responses also highlighted the importance of asking questions and letting people tell their stories. The principles with which my interviewees approached their interactions with people experiencing homelessness at end of life reflected key elements of narrative-based medicine. As evident by its title, narrative-based medicine centers on storytelling, validating the uniqueness of each patient's story and life, and recognizing how physicians can understand their patients and their emotions better and strengthen connections (Zaharias 2018). It increases the awareness of physicians to a need to understand and listen, rather than to focus on problem solving (Zaharias 2018). My conversations with people working with individuals experiencing homelessness highlight how central this listening ability is. Beyond macro-level changes to structural policy or healthcare access, they emphasized the key importance of person-to-person interactions. Beyond anything, it was compassion, empathy, and a willingness to listen that built caring, trusting relationships. When I asked my interviewees about the greatest joys of their work, they almost always talked about the people that they worked with and the relationships which they had with them.

> While I am all about changing things on a broad macro population level, it is the the individual cases and helping people, whether it's in my personal life and buying a bus ticket for someone who needs it out on the street in Providence or in my professional life and working with and hearing this one success case where I helped make the right connection, that keeps me motivated and keeps me grounded in the reality of how important the work is. (Director at a healthcare governmental organization)

The person-on-person connections were a key reminder of why people were doing the work that they did, and it centered the way that they approached their work. A social worker at a community based organization echoed a similar love of these connections:

> I love talking with the people we get to talk with, just pure and simple. I've been doing street outreach since I was a first year undergrad and I have been doing it ever since. And I love it as much today as I did the day that I started. You meet incredible people. Incredible, real, creative, funny people. **And I think that at the end of the day, what**

> **keeps me coming back is I really love the connections we get to make with people that society at best ignores and at worst actively hates.** And there's certainly joys when we see someone get housing and we see someone get income, we see someone get reunited with their family or be able to keep…custody of a child but **all those sort of more discrete joys are secondary to just the love of connection with humans that aren't sort of in the mainstream of our society**. (Social worker at a community based organization)

Interviewees also described the sense of community which they felt within end of life care organizations as well as among the populations which they worked with. For some this was evident in working with people who recognized the challenges which they navigated on a daily basis, and provided “tremendous collegial support” (Chaplain at a hospice center). For others, colleagues and people experiencing homelessness allowed them to maneuver grief after the passing of a patient experiencing homelessness: it “has been helpful. Just feeling like we're not all going through it alone…It certainly doesn't make it easy, but it certainly makes it feel more supportive” (Psychiatrist at a behavioral health center and community based organization).

A psychiatrist also described the mutual caretaking which they witnessed while doing outreach on the streets:

> The other thing that I've been struck by too is just **how much mutual caretaking is going on within the homeless community** and being able to witness that. I can't remember a night where we go out and meet with some folks who don't speak about other people that can really use our help as well. Or people sharing resources and looking out for one another, and also looking out for us. People will let us know like, ‘oh be careful over there, there's been some fighting there.’ The inviting nature of the work has been great. (Psychiatrist at a behavioral health center and community based organization)

It is perhaps worth exploring the idea of community because literature has sometimes emphasized how the homeless population is not really a community. Hojdestrand (2009) described the homeless population as an “apathetic community”; though individuals experiencing homelessness built up social networks at soup kitchens or community service centers, every day was so unpredictable that it was difficult to have continuity in meeting up with one another to maintain relationships (Hojdestrand 2009). Though it seems clear from my interviews that there are some key indicators of community in mutual caretaking and resource sharing, I wonder at how people experiencing homelessness in Rhode Island might classify themselves.

My interviewees frequently used the word friendships to describe the relationship between themselves and people experiencing homelessness. A director of outreach and communications at church shared about his friendship with people experiencing homelessness, particularly among those who came to the daily breakfast hosted at a local church.

> Some of the people that I've crossed paths with I've formed lifelong relationships with and they will be friends until my time's up or till their time's up. But it's the joy of going through struggles. We're all broken in some ways. So we navigate the difficulties of this journey together. But we also celebrate the triumphs together. If somebody gets into housing or…gets a job, whatever it might be, those moments we share together…From your circle of friends, you get as much from them as they get from you. And there's great joy and beauty in that. (Director of outreach and communications at a church)

Overall, this chapter illustrates the importance of relationships at end of life, particularly in caregiving for individuals experiencing homelessness. The structures of end of life care center family members as a crucial support network, but as many people experiencing homelessness do not have close relationships with family, my interviewees spoke about how they assumed some of this role. They also described the necessity of trust and continuity of care to build these relationships, which looked very different depending on each individual. Overall, my interviewees operated with the goal of seeing their clients or patients as valuable human beings, often engaging with them beyond a professional relationship. Though service providers acknowledged the difficulties of their work, they never called these patients burdens; rather, they leaned into the joys of making connections and affirming the value of their patients and clients as human beings.

Chapter 4: A Culture that Fears Death?

I. Inevitability of death

Our current U.S. society is focused on improving and extending life. As more medical technologies arise, the imperative to use them becomes an end in itself (Kaufman 2015). Tools like mechanical ventilators, implantable cardiac defibrillators, and kidney dialysis have shown that there are ways to stave off death, even though health might not improve; life-threatening diseases have become chronic conditions (Kaufman 2015). The influence of Medicare in paying for treatments also increases the expectation that they are utilized (Kaufman 2015). This has enabled a dominant cultural tendency to act as though most deaths are premature, simply because current medicine has the capability to “add” time (Kaufman 2015). The length of a life in itself becomes a measure of its value. These advances in medical technology raise important questions: what does it mean to successfully treat someone? What constitutes a treatment benefit? (Kaufman 2015). These are the narratives in the mainstream of medical treatment. People experiencing homelessness at end of life provide a stark contrast; they face death as an inevitability that is constantly present. The prevalence of death among homeless individuals also results in its normalization, to the point where the community is not surprised when people die (Stajduhar et al. 2019).

> A lot of the folks I work with are generally between 30 to 55ish. I've had some participants who have pretty advanced cirrhosis from alcohol use, but **they don't talk about any kind of end of life except that it's going to happen and there's nothing they can do about it**. So it's this matter of fact approach versus talking about services. **It's likely people face so many barriers accessing other services, I'm assuming it's, “why try anything else?”** (Qualitative researcher)

As described, there is an apathy towards death, of people experiencing homelessness feeling like they can do nothing to stop death’s approach. It is also interesting to consider the influence of the type of role which my interviewees have on the way in which they describe this population. I wonder how much of this perceived helplessness and inevitability is from what people experiencing homelessness have expressed, and how much is a reflection of these workers own sense of helplessness in these situations. Especially as most of my interviewees provide direct service to people experiencing homelessness, these questions of helplessness and inevitability may have some personal element to it, as they may feel personal responsibility for being unable to meet the needs of their clients or patients.

Another interviewee shared a story about a person who had been living outside for the past three to four years:

> He had lost a leg in an accident, maybe a year into me knowing him, and navigating the rest of his time just in a wheelchair. Obviously, it made it incredibly difficult for him to get around. And being that he was unsheltered, the obstacles were just so immense. His experience of that I'm sure shortened his time on this earth. He just was so weathered and so beaten up, for lack of a better phrase, from being out and battling the elements, whether it's the dead of summer when it's 100 degrees, or if it was zero degrees in the winter. He went into a facility and got diagnosed with cancer and his time between, it was maybe six weeks he was in the facility and he passed away six weeks later. That's just really heartbreaking when somebody tells you they know they're dying, like they know this is the end of the road. To wrestle with the battles that he faced the last decade of his life of being in crisis, and then also compound that with, "hey, it's pretty clear cut. I know I've got very little time left." That kind of conversation is very, very hard to have with someone who understands that this is the end of the line….Just gut wrenching, heartbreaking stuff, but…it's common. (Director of outreach and communications at a church)

This story matches with a theme from another study where people experiencing homelessness described witnessing deaths that were "more traumatic and demeaning than deaths that domiciled people may experience" (Hudson et al. 2016). While my research explores the perspectives of people working with individuals experiencing homelessness, it captures a similar idea of the unsettling nature of these deaths. As this director emphasized, this situation felt deeply wrong and troubling: a man with a disability “weathered” and “beaten up” by the outdoors and then dying six weeks after getting a terminal cancer diagnosis.

Interviewees also identified an ever-present sense of death, touching people directly or through the stories of people who they know well.

> **Death is always present, and it feels like it's always around the corner**. There’s often folks that I either knew very well or knew through other people, hearing about people dying. It's not that uncommon that people might wonder or think that somebody may have died and they actually haven't; they've maybe gone to a hospital or disappeared, but it just points to **that fear of death lurking in the background for everybody**. (Psychiatrist at a behavioral health center and community based organization)

Song et al. (2007) also speaks to this ubiquity of death, as a force which informs every aspect of the lives of people experiencing homelessness. These experiences informed their fears, hopes, and wishes for medical care and dying, as well as everyday risk-minimizing behavior (Song et al. 2007). The burden of witnessing these deaths led to fatalism, as a way to cope with pain and fear caused by the inevitability of death (Song et al. 2007). Hudson et al. (2016) described homelessness as “a life filled with fear” (Hudson et al. 2016). The responses of my interviewees highlighted a sense of fear but more often one of acceptance, of the inevitability of death, even if potentially helpful or curative medical services might have been available. This led another interviewee to question the role of housing instability in influencing how individuals experiencing homelessness approached medical decision making:

> We recently worked with a couple out of our South County office who were in the process of an eviction and when they had about a week left in their housing, she found out she had stage four lung cancer…She chose to not seek treatment for either so she's on hospice now and was able to get into a nursing home facility. **You just kind of wonder, is the housing instability responsible for her decision making?**...She was going to be unhoused, she's going to be unsheltered. There were no other options. Is that why she chose not to seek treatment? (Director of integrated care management at a federally qualified health center (FQHC))

If we return to the earlier idea from Kaufmann of how the US tends to use all means of medical technologies to stave off death, and to the valuing of lives based on length, it becomes evident that homeless lives are valued less than other lives. And just as stigma about individuals experiencing homelessness often blames a person for their situation, I wonder how people experiencing homelessness may be blamed for their own deaths in not seeking out medical treatment. We may go round and round talking about how it is pointless to provide certain medical services to individuals experiencing homelessness because it is unlikely that they will utilize them, but in doing so, we deny their right to make a choice. We deny the responsibility to provide enough resources so that people experiencing homelessness actually have the agency to make a choice. This sense of the inevitability of death comes from society and structures, from the denial of care and services, but also from the acceptance that it is normal for people experiencing homelessness to face death at any time, and nothing can be done to prevent it. Thus, society promotes a different valuing of lives, and people experiencing homelessness have come to internalize it.

II. Premature aging and unexpected deaths

My research emphasized the ways in which the nature of aging and death in people experiencing homelessness differ from the general population. Interviewees identified the average life expectancy of people experiencing homelessness to be about 50 years old. A study of Polish individuals found the average life expectancy of a person experiencing homelessness to be 17.5 years shorter than the general population, with average age at death being 56 years old for a male and 52 years old for a female (Romaszko et al. 2017). Interestingly, there is no nation-wide parallel study in U.S. scholarship for the average life expectancy of people experiencing homelessness. A brief by the National Health Care for the Homeless Council noted that few cities or counties in the US reported the age of people who died while unhoused, though data from a few jurisdictions did illustrate that more than half of deaths were among people aged 45 and older (“National Homeless Mortality Overview” 2020). Sacramento county calculated women experiencing homelessness to have an average age of death of 45 years old and men 53 years old (“National Homeless Mortality Overview” 2020). This lack of data returns to an earlier argument about the invisibility of the homeless population, and how bureaucratic decisions render their lives and needs unseen.

My interviewees also noted that people they worked with who were in their 40s and 50s often had ailments which were typically seen in 60 or 70 year olds. Studies on this topic have found similar trends in premature aging, finding that older individuals experiencing homelessness have geriatric medical conditions that match with individuals in the general population at least 20 years older (Culhane et al. 2019). This also raises problems, because while these individuals 65 and younger may have bodies which resemble people 70 or 80 years old, they do not qualify for Medicare (“Homelessness Among Elderly Persons,” 2009).

Yet, my interviewees also emphasized that many individuals who they worked with did not reach this age, due to premature and unexpected deaths. One interviewee described the helplessness that came with this:

> One of the hardest things has been the unexpected nature of how folks are dying. It just feels very different there than elsewhere….and there's no chance to intervene in the way that we would hope to. (Psychiatrist at a behavioral health center and community based organization)

This interviewee went on to describe the nature of these unexpected deaths:

> With the people I work with who are experiencing homelessness, I am always struck by death always being present, in the sense that there's a high rate of premature death in

> folks who were experiencing homelessness, and lots of overdose deaths. Most weeks clients are talking to me about how so-and-so died and they're impacted by it, or there will be a memorial setup where we're doing outreach related to someone who recently died. And it feels more abrupt, unexpected, versus a gradual course where people are able to plan around it and say their goodbyes. They feel more like deaths related to external causes, such as overdose. There is a higher suicide rate in those experiencing homelessness, certainly, as well. But I would say by far, substance related deaths have been the most common, as well as deaths related to violence. What I'm struck by is not the people who died themselves, but how it impacts folks around them. There's certainly been a handful of people that have had terminal conditions, but that's been way more rare. It's been more these unexpected things that come up. (Psychiatrist at a behavioral health center and community based organization)

Moments like this in the interviews were difficult because I could feel a deep pain and sadness from my interviewees. This psychiatrist emphasized the relationality of death; this is not something that only affected an individual, but was felt deeply by friends and acquaintances in the community. The unpredictable and sudden nature of death among individuals experiencing homelessness might offer further insight into why so many reflect on death as an inevitability.

Here, the interviewee identifies suicide, overdose, and violence as reasons for death. I focus specifically on substance use because this was a theme which I addressed in the first chapter. A study of adults experiencing homelessness in Boston in 2013 found that the rate of deaths caused by drug overdose was 20 times higher than that which was found in the general population; similar findings were identified in New York City and San Francisco (Baggett et al. 2013). A more recent study found that of a cohort of over 60,000 individuals experiencing homelessness in Boston, drug overdose was responsible for 1 in 4 deaths (Fine et al. 2022). Specifically in Rhode Island, of 142 individuals who died of drug overdose in 2016, 7.1% of them were people experiencing homelessness (McDonald et al. 2018).

A social worker at a community based organization acknowledged the unexpected nature of death in this population, but pushed back against how this might reduce people's conception of the need for end of life planning.

> **I feel like end of life care for folks experiencing homelessness gets lost because people don't think that there's ever a place for planful end of life for people experiencing homelessness**. **Because so many people experiencing homelessness die suddenly…**People die of violence. For example, people get hit by cars, people get attacked by partners, people die of overdoses or suicide…there's a lot of ways that people experiencing homelessness die at a disproportionate rate, in sudden ways, where end of life care never factors in. So I don't think people think about it very much. And because there's relatively few people experiencing homelessness who are older, in their 70s or 80s, I don't know if it's what jumps to mind for people. **So by and large, I feel like the general public doesn't think about it, which is a huge problem, because even though certainly these sudden deaths happen, there's also these situations where there is room to plan, to provide good care for someone if we got our act together to do it**. (Social worker at a community based organization)

III. A population in the present or looking to the future

This conversation with the social worker at a community based organization ties into our next segment on the question of what role end of life planning should play for individuals experiencing homelessness. They key into how sudden deaths, as well as the lack of visibility of elderly or terminally ill people experiencing homelessness, allow this subject to slip from the mind of the general public. Yet, as this social worker argues, there is a place for planful end of life care for people experiencing homelessness.

Literature on this topic engages in a discussion of whether individuals experiencing homelessness tend to look towards long term needs or solely live in the present. For example, seeking after basics like meals or a bed meant that healthcare often fell to the bottom of the list of priorities for people experiencing homelessness (Hudson et al. 2016; Stajduhar et al. 2019). This matched with perspectives which my interviewees expressed:

> When we meet people who are just financially needy, nevermind, homeless, it's…"If I can't pay my electric bill or if I can't afford food, I'm really not going to be thinking about my existential, philosophical challenges facing the end of my life." And so with the homeless population that's just so much larger. (Social worker at a hospice center)

Desjarlais' ethnographic work highlights the ways in which people experiencing homelessness live a life which excludes them from truly experiencing life and actively acting and observing the world. Particularly in shelters, he noted how residents struggled along, focusing solely on survival and existence and nothing more (Desjarlais, 1994). This ethnography reveals the concept of cyclical time, life without direction and focused solely on survival goals; ultimately, leading to a sense of purposelessness in life (Desjarlais 1994). Yet, though some studies emphasized that people experiencing homelessness are too focused on survival to think about end of life care or death (Stajduhar et al. 2019), much of the literature emphasizes that death and end of life care are still topics of concern for people experiencing homelessness (de Veer et al. 2018; Hudson et al. 2016). Just like others, people experiencing homelessness want to experience a "good death," which includes compassion, dying peacefully without suffering, reconciling with important people in their lives, company from someone (family member or friend), and being in a familiar environment (Hudson et al. 2016). Yet despite a desire for this "good death," most individuals experiencing homelessness are unable to access palliative care until the late stages of their illness, if at all, and many die alone (Stajduhar et al. 2019).

Given the context of Rhode Island, which had the second hospice facility in the United States, founded in 1976, we might expect for there to be a pattern of greater end of life care seeking ("Hope Hospice & Palliative Care Rhode Island Celebrates 40 Years," 2016). A chaplain at a hospice center talked about the commitment of its medical directors to educating healthcare providers in the community about hospice, when to refer people to it, and how to have difficult conversations with their patients about end of life. They went on to emphasize the importance of Rhode Island's history of hospice:

> If you and I were sitting in Oklahoma or Mississippi or places where maybe hospice has less of a history and is less integrated into the overall healthcare system, this might be a really different conversation that we'd be having today…When a hospice such as ours has been around 40 years and counting, there are still people who don't know what hospice is, but they're becoming more few and far between…**it's just sort of part of the fabric of Rhode Island culture at this point**. (Chaplain at a hospice center)

It is difficult to find concrete information that points to ways in which hospice has been integrated into Rhode Island culture. However, a nation-wide study conducted in 2022 found that decedents in Rhode Island were among the least likely to enter hospice from the community, with only about 30% of the population entering; this was contrasted to percentages of over 60% from states like Vermont, Oregon, and Idaho (Teno et al. 2022).

Interviewees called attention to this contrast between a hospice presence and a lack of hospice access and usage:

> We pride ourselves as a society with hospice, that we want people to die with dignity and respect. And yet we don't provide the space for people to do that who don't already have a home. And sometimes people will be in the midst of being evicted when they're diagnosed with a terminal disease. And so you've got this added layer of I'm going to be dying soon. And I also don't have a place to live… it's heartbreaking. (Chaplain at a hospice center)

Interestingly, past research has emphasized a fear on the part of professionals to speak with people experiencing homelessness about death (de Veer et al. 2018; Shulman et al. 2017). There is generally a sense of the fragility and vulnerability of homeless people, which professionals worried would be affected by discussions of advance care planning (ACP) (Shulman et al. 2017). Professionals worried about how these conversations about care planning might amplify a patient experiencing homelessness's sense of loneliness, anxiety, and fear about death (Håkanson et al. 2016). Additionally, they feared that having these types of conversations might make their clients feel as though they were being abandoned (Hudson et al. 2017). In contrast, while a significant body of literature focuses on the fear around what effect such conversations might have on individuals experiencing homelessness, my research seemed to highlight that end of life care planning was simply not a priority for people experiencing homelessness.

> Because the focus is so much on how people are just going to get through tonight and… the next couple of days, short term thinking is necessary for survival. It [end of life care planning] almost gets sidelined. It gets pushed to "that's not something that's important right now." One of the reasons it doesn't come up as much is because the focus is just on basic survival needs at the moment and then once somebody is connected to housing or in a more stable place, or they've worked on getting into substance recovery…[it] feels like then there's room for other other things…**this isn't a purposeful attitude; it's not that it doesn't matter. I think it's more that it's not on the priority list right then, and it just doesn't always become front and center**. (Psychiatrist at a behavioral health center and community based organization)

This interviewee describes a rather overwhelming process of how basic needs supersede any future planning of this nature. This response also used similar language to a study by Ko & Nelson-Becker (2014) which found that many individuals experiencing homelessness did not consider advance care planning a priority concern, as day-by-day survival was their main concern and challenge; however, Ko & Nelson-Becker still did acknowledge the usefulness of advance care planning. From the perspective of service providers, Davis-Berman (2016) also found that though service providers understood the importance of end of life care for the homeless, they seemed too overwhelmed addressing acute healthcare needs to redirect their attention towards programs for end of life care. In some ways, it becomes evident that this is the case among the population which I studied. Yet, though lack of knowledge about end of life care and its specific importance for people experiencing homelessness certainly plays a role, as

Davis-Berman (2016) also described, it sometimes felt as though inevitability and despair shaped professionals' approach to end of life care.

> We find a lot of times that **people die the way they live**. So if somebody lived in a way that was a lot of suffering, where they didn't have their basic needs being met, where they lacked family, lacked community. We see a lot of times that that is unfortunately the way they're going to die too. (Chaplain at a hospice center)
>
> We often discussed, as part of a team, the fact that **people tend to die very much the way they live**….we always tried to help people meet their goals…within what was possible. But there was very much the sense that we couldn't fix people's lives, that you could only be there to the extent that it was possible and that some of the larger issues that people had been facing their whole life remain as they became terminally ill. (Associate professor at the School of Public Health)

The phrase "people die the way they live" implies a realism in the ways in which my interviewees approached their care for people experiencing homelessness, but I also wonder how it compromises the type of opportunities for care that people are offered. Some of my interviewees did identify how they provided advanced care planning to their clients experiencing homelessness:

> When it comes to advanced care planning with the patients that we work with, they usually don't have someone that they go to and connect with to come up with that plan. The planning is basically providing them the support and making sure that they are getting their medical needs and just feeling safe and at the end, whatever they want. It's a person centered plan and a lot of times they don't always voice that opinion because they're so isolated. (Housing specialist at a federally qualified health center (FQHC))

Overall, critiques and fears about pursuing end of life care planning for people experiencing homelessness are valid points. But I still struggle to see why these should prevent offering an option to engage in end of life care planning. After all, as the federal Patient Self-Determination Act (PSDA) of 1991 mandates, healthcare institutions *must* ask their patients about advance directives (ADs) and whether they would like to fill one out (Song et al. 2008). Song et al. (2008) also found that most people experiencing homelessness will fill out an AD if given the chance, and that doing so had a significant impact in reducing worry. While the AD completion rate in populations described by other studies was around 20%, Song et al. (2008) found that when given an opportunity to fill out an AD, 30% of individuals experiencing homelessness took the chance. Additionally, when offered simple one-on-one counseling guidance, this number increased to 59% (Song et al. 2008). Thus, it only seems right to at least offer people the opportunity to engage in end of life planning, even if they might not take the opportunity.

IV. Invisibility of this population

When asked, "what is the proportion of the patients that you see who are experiencing homelessness?", it was interesting to note the responses of participants:

> Very small…unless it's hidden homelessness, meaning somebody who might be by one definition described as homeless because they don't have their own housing but they might be living with a relative. In terms of strictly either someone who's on the streets, or someone who's in a shelter, I would say it's very small, maybe 1%. (Chaplain at a hospice center)
>
> I would say probably, to our knowledge…probably like 1 to 2%. But if we were to dig a little bit deeper and work more proactively with the shelters, with the hospitals, with people who specifically work with the homeless population, I think that that number could probably be higher. (Chaplain at a hospice center)
>
> It's definitely a small percentage…I wouldn't say I have one person a month…It's small. I don't know. It's interesting to me. You say where did these people go? They probably ended up in the hospital. (Social worker at a hospice center)

Understandably, few had an exact number to provide, but it was fascinating to see how they acknowledged ways in which homelessness might go unseen. Even at facilities that provided more wraparound support to people experiencing homelessness, they did not fully know which of their patients did not have housing.

On a larger scale, another interviewee emphasized how the homeless population was overlooked and invisible at a bureaucratic level:

> The majority of my work here [in RI] is national in scope, so we…use administrative claims data to look at end of life care utilization. And homelessness is not an indicator that's…part of claims data. People would need to have a billing address to be receiving services and the population without such a billing address probably get served by hospitals and other institutions, but it's unclear…How does that translate to the utilization that I get to see looking at someone's Medicare claims? **If there isn't a stable address to be billing at, it's probably a population that is quite underrepresented in our administrative claims data work.** So that's certainly a shortcoming. (Associate professor at the School of Public Health)

This interviewee demonstrated that national data does not account for end of life care utilization for people experiencing homelessness. Without data on this topic, how is it possible to know on a national scale whether or not these people are able to access end of life care? With only small city or state-wide case studies or analyses, it is difficult to find larger trends of access or to identify patterns of certain areas which might be doing a better job at providing access. With this type of data, it would be possible to determine strategies that might work on a much broader scale, as well as identify which cities or states have greater success in providing access, and how this success might be replicated in other parts of the country.

V. Larger reflections of society

While my research focused on the particular population of people experiencing homelessness at end of life, it was fascinating to see the ways in which my interviewees expanded discussions about the topic to reflect larger issues in society, such as end of life care, the elderly, and a fear of death. The particular issue which I investigated is not exclusive to other issues; rather, in examining end of life care for such a vulnerable population, it provides a much starker contrast in which to view existing issues which might be more hidden among more privileged populations.

One such larger topic was of a larger cultural disrespect for the elderly and the wisdom which they have to share. A chaplain at a hospice center described the knowledge which can be learned from the elderly:

> We get to learn how to live, as they reflect on how their life has been and how they want to die….We get so much history and life review and experience and these beautiful gems and nuggets of information, especially from our elderly population who have seen things. **In the US, we don't hold the elderly in the same reverence as some other cultures, and that's such a failure on our part** because I think that our age would not struggle as much if we would maybe just connect a little bit more with the people who have been there, who have seen things, who have heard things. And not that they can give us the Cliff notes but maybe they can give us some information that can alleviate our suffering. That's one of the joys of this work, is that **you really get to learn how to live through the people who are dying**. (Chaplain at a hospice center)

As this interviewee described, in casting aside certain people, we lose the value of accessing a whole pool of knowledge and life experience.

Interviewees also addressed a much larger theme of a fear of death in the US, and an unwillingness to accept palliative or hospice care measures.

> Our American culture seems to clash with the whole idea of accepting a situation and working with more palliative interventions towards a good death…I think that this is perhaps in some part due to our own American sort of belief system, but healthcare providers don't seem to refer people to hospice until it's really late. (CEO of a social services organization)

This also ties into the way that death was seen as a taboo topic, and the theme of invisibility extended beyond people experiencing homelessness.

> If you think about people in nursing homes…there's no real acknowledgement about how this is the last place you're going to be and death is pretty well hidden in nursing homes. Close all the doors, get the person out, nobody talks about it. It's not your relatives, so information isn't shared. **So if in that setting, we don't do a good job, then when you**

> **have people who don't even have a room or a place to live…?** (Social worker at a hospice center)

This question is so telling and very worth repeating: If we don't do a good job of addressing death among people in nursing homes, how much worse of a job are we doing in respecting and honoring the deaths of people experiencing homelessness at end of life?

Interviewees also emphasized how the lack of knowledge about end of life care was detrimental to all populations:

> We're all going to be here [at end of life] at some point and understanding the process and having the knowledge makes it a lot less scary. Because death to some people is really scary. The uncertainty, the unknown, not being in control of some things. Giving people that knowledge base, being able to serve people and giving them the knowledge, "this is what is going to happen, let's talk about it." And giving people the space to unburden themselves of whatever is causing them any pain, whether it is physical, spiritual, emotional. (Chaplain at a hospice center)

An overall emphasis on shared commonality and humanness was also very important. Interviewees described how end of life is difficult for everybody, but is also something that becomes more understandable when we realize that everyone will eventually face it:

> Even for folks who are housed or have been housed all their lives, end of life transitions can be difficult mentally for people. It's hard to say, "I can't do this anymore," or "I don't have the ability to do what I used to be able to do"...I have older parents and I know that that's what they struggle with. They're able to live on their own for now but when they have to make that transition to assisted living or the nursing home, it's going to be a difficult transition mentally. (Director at a community based organization)

> We're all going to be there too. And that's also really important for people to remember that each and every one of us…Anything…that's alive is going to die. We are all going to be there at some point: we're either all going to be caregivers, or we are all going to be on our deathbed. (Chaplain at a hospice center)

This chapter speaks to the inevitability of death among people experiencing homelessness, and the ways in which people are constantly exposed to death to the point that it is almost normalized. This constant presence of death is also attributed to the premature aging of people experiencing homelessness, as well as the frequency of unexpected deaths. These unexpected deaths and the nature of living day to day means that people experiencing homelessness are not often given an opportunity to engage with end of life care planning. Their experiences with homelessness also often remain invisible, both in interactions with service providers and on a bureaucratic level through administrative data. Finally, my interviewees describe how experiences of people experiencing homelessness extend to larger reflections of society, particularly on the topic of death and the elderly.

Conclusion

I. Successful access to end of life care

The central theme among individuals experiencing homelessness who were able to access end of life care was that they had people fighting for them and their rights. This meant having service providers involved at every step of the way, willing to meet their expressed needs and to think creatively about feasible and realistic ways of meeting them. While my interviews highlighted a handful of successful cases where people accessed end of life care, the following were some of the most powerful pieces of evidence of the kind of dedication which this required. A director of integrated care management at a federally qualified health center (FQHC) described a patient who had been homeless for over 15 years:

> She's got some other significant behavioral health substance use disorder issues and at one point nobody even knew how to get in touch with her. She would just randomly show up highly intoxicated at all times of the day and just really impossible to get anything accomplished. **But both [housing specialists] were extremely persistent and consistent with her and so now…they're seeing the benefit of that. Not giving up on someone because other people did give up on this person.** She was nearly impossible to work with but now that she's housed, it's so much easier to access her. She's super open to help and always has been. She just didn't know how to appropriately reach out for it. (Director of integrated care management at a federally qualified health center (FQHC))

This story speaks strongly to the power of persistent follow up and dedication, but also to the importance of housing as a first step to getting people access to medical care. A housing specialist at a community federally qualified health center (FQHC) also described another patient who had recently been housed. He had been unhoused for at least 20 years.

> …he's elderly, so he aged while being homeless…I think that maybe contributed to this patient actually finally accepting and seeking help: his age and he's getting older and probably can't really sustain living outside any longer. So even though it's been very challenging for our staff to work with him because of his behavioral health barriers and he has been in and out of the Department of Corrections, we finally got a place. Like I

> said, he's being housed today. (Housing specialist at a community federally qualified health center (FQHC))

This case highlights how important the will of the individual experiencing homelessness is in seeking care. The care and attention that service providers offer is critical, but they don't amount to much without a desire from the individual experiencing homelessness. Both of the above examples refer more to access to housing, rather than specifically to end of life care; however, given my findings, getting housing, or at least a space out of which it is possible to engage with consistent follow up, is a critical step towards accessing end of life care, as palliative care is extremely difficult without a housing space to work from.

Finally, it was interesting how service providers engaged with people entering end of life care at different stages; thus, some examples only described the experience with end of life care, not the journey to access it. A director of outreach and communications at a church described his interactions with end of life care facilities for two different individuals experiencing homelessness as "top notch," with "incredible" staff that made the experience very comfortable. Obviously, this is not a universal experience, but it does inspire hope that the facilities in Rhode Island have compassionate practices once patients are actually able to access their services.

II. Effective models of care

On examining the literature for other effective models of end of life care in North America, I found the following projects and programs.

The Ottawa Inner City Health Project was a pilot study meant to improve healthcare access for adults experiencing homelessness. In 2001, a 15-bed shelter-based palliative care pilot was created for terminally ill individuals experiencing homelessness (Podymow et al. 2006). This model included food, housing, nursing, client care workers, medical supplies, medications, and physicians (Pineau 2014). This program was found to significantly reduce the healthcare costs per individual, saving an estimated $1.39 million for the 28 patients included in the study (Podymow et al. 2006). Broken down to a daily cost, care amounted to $125 per patient instead of $684 for traditional palliative care and $633 for tertiary hospital care (Pineau 2014).

The Inn Between in Salt Lake City, Utah has a similar design, with 24/7 staffing for individuals experiencing homelessness with advanced illnesses (Health Care for the Homeless Clinicians' Network 2018).

The Mobile Palliative Care Program for Homeless Individuals (MPCH), piloted in Seattle in 2014, connects ill individuals with healthcare and other services through funding from Medicaid or the hospital (Health Care for the Homeless Clinicians' Network 2018). It found that emergency room visits had decreased by 50% and hospital stays fell by 25% for patients enrolled in the program for six months (Health Care for the Homeless Clinicians' Network 2018).

Palliative Education and Care for the Homeless (PEACH) in Toronto provides community services in shelters and on the streets, as well as providing information and training to homeless service providers (Health Care for the Homeless Clinicians' Network 2018).

Circle the City Medical Respite in Phoenix, Arizona is a 50-bed medical respite facility that partners with a local hospice provider (Health Care for the Homeless Clinicians' Network 2018).

These models highlight the effectiveness of hospice and palliative care programs specifically for people experiencing homelessness. They helped reduce costs, as well as improved care. By providing care specifically tailored to this population of individuals, particularly in eliminating the barrier of housing, at least temporarily, these programs addressed several major barriers to care.

There are also new initiatives in Rhode Island, such as the 24/7 warming station and a medical respite pilot. The 24/7 warming station, established in mid December, provides 50 to 60 beds where unsheltered individuals experiencing homelessness can go to get out of the cold. At this warming station, people can also be triaged for other resources that they need; though this may include access to end of life care services, interviewees noted that this was not an ideal location for these services because of the open bay structure of the space. The medical respite pilot is a collaborative project between a governmental organization, a hospice center, and a shelter. It aims to provide acute care and shelter for people experiencing homelessness, with the potential for referral to other providers or services. It is an important step in linking end of life care to programs that meet individuals experiencing homelessness in their community, as well as building a space for interdisciplinary work between service providers of different fields.

III. Solutions

I am wary of falling into the trap of thinking that I know enough about this topic to propose viable solutions. There are so many more pieces to examine, so many other factors to consider. However, I have been given a glimpse into some of the realities of providing end of life care and my interviewees have helped me identify some of its most important elements.

A predominant theme is that there is no single specific form of care which would be most appropriate for this population. I initially thought that residential care services, such as hospice, would be the most important form of end of life care; however, as literature and my interviews revealed, individuals have various levels of comfort with institutions. There is a much greater need to meet people where they are at. It would be unlikely that solutions would include a uniform care trajectory or plan, because each case varies so widely. As an associate professor at the School of Public Health said, “there's not a lot of magic fixes that the healthcare system can come up with.” Nearly all of my interviewees advocated for meeting people where they are at:

> People do a lot better when it's decentralized medical care and the street based medicine that meets people where they're at and supports them in their own environments. (Qualitative researcher)

What does meeting people experiencing homelessness at the end of life wherever they are look like? Previous literature talks about the importance of using spaces where people experiencing homelessness feel comfortable, such as shelters, soup kitchens, or syringe exchange programs, for medical services to be available (Hudson et al. 2016). These spaces have lower barriers to care and thus, have an increased capacity to offer end of life care services to individuals experiencing homelessness (McNeil & Guirguis-Younger 2012). This kind of street based medicine was already evident in my research, but it was more often done with a lens of primary care, rather than with the specific goal of identifying people in need of end of life care. Community based organizations are already building consistent relationships with people experiencing homelessness, which has allowed them to determine when end of life intervention and referrals were necessary. However, as evidenced by the effective models of care above, it is essential that there are dedicated services specifically for people experiencing homelessness who require end of life care. The new medical respite pilot in Rhode Island works to partially address this gap in care, but I believe that there also needs to be a dedicated team which engages in street outreach, with the specific goal of identifying people experiencing homelessness who need end of life care.

Care for this population requires flexibility and adaptation, a responsiveness to people with a range of housing statuses, life experiences, and substance use practices. A social worker at a community based organization described the care they provided as “heterogeneous” and rooted in conversations with people experiencing homelessness to “design the best fit [of care] possible together with whatever partners are relevant to their desires.” Flexibility is difficult to systematize and expand to a more national scale. But as this interviewee highlights, and as previous research states, flexibility is essential to increase access to end of life care services for individuals experiencing homelessness (Hudson et al. 2016). Perhaps a handbook of resources listing different service providers, contact information, criteria for programs, and services which they offer could be distributed to everyone within the state. In order to offer this option of flexibility, people must first be equipped with the knowledge about the options which are available. de Veer et al. (2018) emphasizes how critical building a network of palliative care specialists is to help address the needs of people experiencing homelessness. This kind of handbook would also build existing networks of resources between people providing care to individuals experiencing homelessness. It also would not enforce formal strictures on exactly how people ought to create a trajectory of care for their clients; rather, it would give them the tools to craft a unique trajectory of care for each individual.

Other important elements to facilitate service providers’ flexibility include creating more conducive environments for communication between interdisciplinary teams. For most interviewees, this meant having people with different skill sets all working together in the same place; of particular importance was joining together social services, chaplains, palliative or hospice care workers, and associated providers who had done work with people experiencing homelessness *and* people with substance use disorders. As identified earlier in my thesis, a siloing between those working with individuals with substance use disorders and those working with individuals at end of life led to increased difficulty in providing integrated care to these folks. In more intentionally integrating providers who have experience with both fields of substance use disorders and end of life care, this siloed care can be streamlined to provide more effective pain management and unified care. Practically, this might look like having integrated care teams or at least chat functions or email chains which could link two providers with expertise in both of the fields. This would allow for regular communication and collaborative decisions between providers as they create action plans for care. This also relates specifically to the complicated issue of pain management, particularly in how to prescribe medications while knowing a patient had or has a substance use disorder. Research has described how a harm reduction approach, which operates around meeting people where they are at, did not appear to increase substance use in medication and pain control (Podymow et al. 2006). However, this particular study required constant vigilance from staff at a hospice pilot, which raises questions about its feasibility for palliative care with less engagement from providers (Podymow et al. 2006). I believe more integrated care, as described above, would help to mitigate some of the issues of pain management, but it is worth a dedicated pilot in Rhode Island to better understand effective practices.

As to the bureaucratic structures which limit the flexibility of service providers and the resources available to serve this population, a central point for change is in funding. An office manager at a healthcare governmental organization described how connection points between community based organizations and governmental organizations are necessary in order to change funding:

> I feel like we have the most impact when we all connect together, hear others' experiences and responses, and figure out what are the priorities, and what does the population need so we can help formulate the right funding opportunities, and then direct funding in the right ways and also support each other in trying to accomplish this goal. (Office manager at a healthcare governmental organization)

My research revealed that the state government is not in touch with these community based organizations enough to recognize the realities of providing end of life care, or to be knowledgeable about statistics of where people experiencing homelessness at end of life actually end up accessing care. Beyond specific partnerships for things like warming stations or medical respite pilots, it was unclear how much interaction there was between community based organizations, hospice centers, clinics, and governmental organizations. I propose an annual or bi-annual forum or conference that might bring all these people together. When I asked the office manager and director at the governmental organization about their knowledge of the end of life care landscape, they knew very little beyond the formal partners which they had in the community. This also highlights the ways that the voices of service providers and the struggles which they face in providing care to people experiencing homelessness at end of life may go unheard. Having forums like this would spotlight their voices, and keep this governmental organization accountable in how they are working to make actual change to address the barriers within end of life care. It also will increase visibility of difficulties, and build solidarity between service providers as their struggles are affirmed and heard.

Additionally, to address service providers' lack of knowledge about issues for people experiencing homelessness at end of life, some of my interviewees highlighted the importance of having medical and social work students attend outreach routes to people experiencing homelessness alongside other community based organizations. This engagement during training periods exposed students to the stories of people with lived experiences of homelessness, how they became homeless, and the struggles which they face: "the best way to learn about social determinants of health is to go out there and see it and not listen to someone in a classroom, but to listen to somebody who's experiencing it" (Psychiatrist at a behavioral health center and community based organization). Interactions with people experiencing homelessness should be integrated into the education system for people planning to work with underserved populations. Actual engagement builds personal relationships, increases empathy, and also increases the visibility of this population. Engagement like this also opens up doors for people to ask questions about the medical system or social work system as they are being trained, seeking out ways to address gaps in curriculum.

Service providers also identified the ways that they felt that they lacked knowledge about end of life care. Again, the handbook described above could help service providers to communicate with one another and understand more about the range of services available. However, as a physician at a federally qualified health center (FQHC) described earlier, "when you go out of that system into the general medical world, it's a roll of the dice…they're not necessarily there to solve that problem, so they're not as interested in solving it." Specifically for medical providers, there were those who cared to try and address these barriers to care for this population, while there were others who simply did not. Though the National Health Care for the Homeless Council does critical work in educating providers about tools, strategies, and barriers while working with people experiencing homelessness, I worry about the reach that their work has, particularly as those who seek out information from them or attend conferences are those who are already fairly engaged with this population. Perhaps findings on the topic of people experiencing homelessness should become mandated information that service providers must review as a part of their job. I am unsure of how this should look exactly, but present it as something that should be explored further.

IV. Concluding Remarks

This thesis offers a window into the experiences of service providers for people experiencing homelessness at end of life, but the conclusions drawn from this specific population can be applied to the larger landscape of end of life care, the aging population, and the role of families in care. It also highlights larger structural trends which make certain populations invisible. Deciding that people do or not need something without asking for their opinions implies that we have the right to speak for the other people, the right to say that we know what they want. A long history of injustice, oppression, and violence against many population subgroups in the United States tells us the opposite. We *must* engage and listen. When we don't hesitate to ask what hidden or oppressed populations see as their needs, their barriers to meeting these needs, and the effective approaches to counter these barriers, we perpetuate cycles of harm. This points to the importance of research tactics like engaged anthropology, which partners with a community being studied to create an inquiry focus which accounts for what the community thinks should be studied, and allows them to be a part of the process in every way.

The larger structure of end of life care also points to a much broader discussion about what it means to be a "good" and valuable citizen. Limited resources and attention are dedicated to end of life care, which raises many questions: How do we value the elderly? How do we value lives based on the work they can produce, the money they can pay, and the family they can contribute? How does society communicate a different valuing of lives? Is there intrinsic value in each individual simply in being a human being?

Ultimately, over the course of this thesis, I have learned that you can't systematize compassion. You can't structure love. We have much work ahead of us, but it is inspiring to see the sacrifices and the battles which service providers for people experiencing homelessness are willing to take on. At the very root of good end of life care, and any care for that matter, were people who invested deeply in relationships and fought against the barriers that arose.

My greatest hope is that this thesis has value to service providers in gaining insight to the landscape of end of life care for people experiencing homelessness in Rhode Island. I hope that it might also raise broader awareness about the value of investigating this topic more. In no way is this work comprehensive, but I hope that the insight that it does offer may be useful in some way. I plan to distribute my findings to interviewees who I spoke with, and hope to publish a brief of major findings and potentially helpful recommendations in a more public setting, possibly *Street Sights* or the Rhode Island Public Health Association. I also hope to create a shared google document with the names of service providers, their organizations, relevant information, and contacts, which can be distributed among people who work with people experiencing homelessness (assuming that people give permission to be a part of this document). I hope for this to be a living document which people can continue to expand upon.

I will forever be inspired by the work that these service providers do and by the level of dedication which they have to their patients and clients. In whatever path I take in the future, I hope to carry a commitment to uplift other voices and stories, to fight for their value and the right for their needs to be heard and met.

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