Uncertain Destinations: Characterizing the Role of Place in the Later-Life Experiences of Palliative Care Patients Experiencing Homelessness

Ian M. Johnson

A dissertation
submitted in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy

University of Washington
2022

Reading Committee:
Taryn Lindhorst, Chair
Clara Berridge
Megan Moore

Program Authorized to Offer Degree
School of Social Work

University of Washington

Abstract

Uncertain Destinations: Characterizing the Role of Place in the Later-Life Experiences of Palliative Care Patients Experiencing Homelessness

Ian M. Johnson

Chair of the Supervisory Committee
Professor Taryn Lindhorst
School of Social Work

Purpose: Homelessness is a pervasive social injustice that stems from the sociopolitical construction of disposable human life. The shifting age demographics of those experiencing homelessness in the United States exposes the shortcomings and barriers within homelessness response services and safety-net healthcare to address serious illness, disability, and age-related needs. Through a partnership with the only specialty palliative care program for people experiencing homelessness in the United States, the Research, Action & Supportive Care at Later-life for Unhoused Peoples (RASCAL-UP) study aimed to (1) identify barriers to care across a spectrum of services for unhoused people facing serious illness; and (2) examine residential trajectories of unhoused patients over the course of palliative care treatment. *Methods:* A constructivist grounded theory approach was taken. Retrospective chart review of palliative care patients (n=75) was paired with semi-structured interviews with service providers across healthcare and homeless response systems (n=30), as well as observation of palliative care meetings (n=12). *Findings:* An exploratory analysis of patient charts led to the identification of a 4-category qualitative typology of residential trajectories during palliative care enrollment. The Aging & Dying in Place typology showed sustained continuity of care within supportive housing. Providers described permanent supportive housing and low-barrier temporary accommodations as optimal lodging for people experiencing both homelessness and serious illness, due to the relative privacy, autonomy, and peer and community support they offer. Some of these locations, such as Tiny Villages, offer modularity, allowing for personalized adaptations. However, increasing system strains promote burnout among staff and limit supply. There are accessibility barriers in supportive housing, emergency shelters, Single Room Occupancy sites, and hotels and challenges in partnership with health and caregiving services. The Frequent Transitions typology was developed for patients who were unable to establish continuity of care during their palliative care enrollment, moving between locations on the housing care continuum, healthcare institutions, jail, and street-based settings. In these cases, health and housing systems were not able to adequately patch together care. The third typology, Healthcare Institutions as Housing, identified a set of patient experiences characterized by long-term hospitalizations and skilled nursing utilization. Health services within homeless systems, like medical respite, were designed to assist with acute and temporary issues and faced limitations in serving people with aging-related health issues or chronic serious illness. Medical providers noted that access and admission to long-term care services were influenced by system strain and capacity, financial disincentives for taking dual-eligible (i.e., Medicare and Medicaid qualified) patients, perception and stigma of unhoused populations, and limited knowledge of harm reduction, serious mental illness, and trauma. Providers noted the pervasive ideology of punishment as a form of health motivation, and how health policy and practice is not low-barrier. The fourth typology, Housing as Palliation, illustrated a pathway in which patients secured housing later in their illness trajectory, suggesting their prognoses and symptoms activated a system of support for older, disabled, and/or seriously-ill people that isn't available until one is deemed most-vulnerable. *Discussion*: This study offers an initial framework for understanding how current systems of care fall short for people facing simultaneous homelessness and serious illness, and opportunities to address housing and health service gaps. Potential advances in closing the gap between health and housing services include incentivized interdisciplinary, cross-system education, training, and consultation that focuses on both homelessness and palliative care, as well as mobile health and low-barrier housing interventions that attend to chronic and high medical acuity. Researchers can contribute implementation science tools to measure and translate the innovative aging and health programming and services emerging in the spaces where housing care continuum, healthcare, government aging and disability services, and community mutual aid intersect.

Keywords: homelessness, place of care, palliative care, end-of-life, chronic illness

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ACKNOWLEDGMENTS

I would first like to thank Dr. Taryn Lindhorst for her unrelenting support throughout the entire doctoral study process—both your care and insight reaches soul-deep. I would also like to thank Dr. Clara Berridge, whose knowledge of and love for critical gerontology and disability scholarship has not only inspired a joyfully-endless reading list but has given me the space to embrace my own enthusiasm for research. I would also like to thank Drs. Megan Moore and Lynne Manzo for their support on both my qualifying paper and dissertation. My appreciation goes out to the faculty of UW Disability Studies master's certificate program, namely Dr. Heather Evans, who was a powerful guiding force in helping me to find my footing. I am also grateful for Wendy Lustbader, J'May Rivara, Lynn Behar, and Drs. Nancy Hooyman, Terri Lewinson, and Tam Perry-- I exit my doctorate program a changed person because of your collective encouragement, wisdom, and grace.

Kriya, I am so happy we wrote our dissertations together. It would've been double the torture and half of the fun without your camaraderie—I love you. I want to issue a shout-out to the healers who were with me on the journey, especially Kelsey, Jennifer, and, of course, Victor. Thank you to the musicians, poets, authors, and other artists who get us through personal, national, and global crises. Thank you to my dear friends and family (Nicole, Corey & Carmela; Sunny & Aja; the doctoral student community in social work and education; the Pin Pals; GSA colleagues like Austin, Nicholas, Anyah, & Sarah; Michael Louderback and Nicole Greenwald; Mandala, Tara & the Nanays; Amy & Bryan; Kate & James; the DeValks; Mama Kosh and Stephanie) for your love, your laughter, your commiseration, your patience, your playlists, and your memes. Your support in this life is what I value the most.

Many thanks to the people who convinced me that I could do this before I started— Nancy Giunta; Laura Berenson; Vickie Fossella; mentors and friends at The Bridge; Chuck Finlon; Christine LaCerva and others from Social Therapy Group; the CUNY Hunter alumni network; my students. I'm so grateful that we relate to each other as the people we are becoming.

This project would not have been possible without the person who is now both a dear friend and hopefully, a lifelong colleague, Michael Light. I'm endlessly inspired by the work of the mobile homeless palliative care team and y'all's capacity for compassion, joy, and humor in traversing the borders of "medical apartheid," to borrow Joe's words. I hope this dissertation is the beginning of our long journey toward seeking housing and health justice together.

This culminating moment would never have happened without the trust of the people who have generously let me into their lives (and sometimes, their deaths) as a social worker or therapist. May this document be my promise to honor you, our work, and your legacies.

CHAPTER 1

INTRODUCTION

Gerontological social work has long been involved in addressing the heterogenous housing concerns of older adults (Frochen & Pynoos, 2017). Scholarship on housing and older adults has argued that special considerations must be made in considering older adults' social networks (Gardner, 2011) overall health (Annear et al., 2014), and economic well-being (Koss & Ekerdt, 2017). Similarly, end-of-life healthcare services have noted the importance of addressing serious illness and end-of-life needs within a patient's preferred place of care (Teno et al., 2004), which most often is indicated as a patient's home environment (Bell et al., 2010).

Advancements in facilitating congruence in place of care have shed light on geographic, racial, and socioeconomic inequities associated with where patients die (Gruneir et al., 2007). Receiving palliative care and end-of-life services at home is much less likely for people in poverty, particularly poor people of color, disabled people, and LGBT peoples (Estrada et al., 2021; Cross et al., 2021). The continuity of care which facilitates congruence between actual and preferred place of care during serious illness (Chen, Chen & Kuo, 2020) is less likely when older adults face displacement and housing loss, the experience of unstable housing. Older people may manage co-occurring financial demands and medical comorbidities while lacking robust social support, health resources, or housing options (Lewinson, 2014). Interlocking environmental challenges such as finances and health can both prompt voluntary relocation (Perry, 2014) when faced with constrained choices, or subject older adults to involuntary relocation and removal (Gonzales et al., 2019, Perry et al., 2021).

Once homeless, there are few options for older adults that realistically support holistic health, re-establish desired housing, and sustain them as serious illness progresses (Canham et al., 2021). Unhoused elders face barriers to care during their illness trajectories, including stigma from health professionals, distrust of medical systems, cost and coverage, logistic problems in accessing medical equipment or continuity of care while unhoused, and suspension of community-based services due to perceived danger by service providers (Davis-Berman, 2016). These barriers influence both where care takes place and processes around attaining psychosocial later-life goals. While the idealized and most desirable place for aging and end-of-life care may most frequently be one's historical place of residence, the assumed absence of such a place in the lives of *home-less* older adults does not justify the lack of theoretical attention, empirical description, or development of practical responses on the subject.

In this introductory chapter, I operationalize U.S. homelessness and place it within the context of population aging. I then describe the current housing care continuum responses to aging. I situate myself and experiences in relationship to the study. I conclude this chapter by providing a description of the dissertation's primary aims and outlining the research questions posed in the results chapters.

Homelessness from a Life Course Perspective

Historical and political events throughout the lifetimes of contemporary older adults have shaped our current systems of care and punishment. Culturally viewed as financially secure and 'reinventing retirement' with flexible spending (Tavener, Byles, & Loxton, 2013), Baby Boomers, 57-76 years of age in the year 2022, were the most economically-stratified age cohort to enter midlife (Leicht & Fitzgerald, 2014). Specifically for people of color (Sharp & Hall, 2014), LGBTQ individuals (Wilson et al., 2020), and disabled people (Parish et al., 2010) in the Boomer cohort, significant life course events have threatened financial, employment, and housing security (Crystal, Shea, & Reyes, 2017). Examples of socio-political and economic disruptions across the period of 1946 – 1964 (Baby Boomer's birth cohorts) include the following. Psychiatric deinstitutionalization in the 1950s and 1960s was never adequately funded once Reagan cut funding for the nascent community mental health system (Dear & Wolch, 2015). The forcible draft of the Vietnam War (Tsai et al., 2016), racialized mass incarceration through War on Drugs legislation (Fornili, 2018), and the HIV/AIDS epidemic (Furlotte & Schwartz, 2017) added to the trauma of a cohort and the lack of federal funding and legislation to address domestic community issues, particularly in the Black communities. Co-occurring inflation and wage stagnation in the mid-1970s to early 1980s cut into the lifelong earning potential for many (Li & Lin, 2016). This confluence of factors generated a high rate of chronic homelessness among Baby Boomers.

In the 1990s, white, middle-class professionals and families began migrating back to urban centers from suburbs (Herbert & Beckett, 2009). Urban redevelopment led to anti-homeless legislation and hostile neighborhood sentiments against low-income housing, causing a dwindling affordable housing supply and damaging the natural infrastructures that prevented displacement in existing communities (Eisenberg, 2017). More recent factors like the 2007 recession (Noelke & Beckfield, 2014), rising out-of-pocket medical expenditures (Cutshaw et al., 2016), and the COVID-19 pandemic (Nilsen, 2021) have magnified risk of housing precarity for older adults. In addition to the portion of older adults experiencing chronic homelessness, many older people with conventional housing histories now experience homelessness for the first time in later life (Grenier & Phillipson, 2018).

Responses to Population Aging in Homeless Contexts

Homelessness as a Phenomenon

Critically Defining & Estimating Homelessness

The most recent HUD Point in Time (2020) counts estimate that across the nation, 580,466 people experienced homelessness on any given night. However, there are significant variations between cities in methodological approach (Schneider, Brisson, & Burnes, 2016) and broad critique of the quality of data collected (Weare, 2019). When considering both suggested methodological improvements and a definition of homelessness inclusive of those experiencing a type of homelessness rendered less perceivable (such as doubling up or moving between family and friends), researchers have found upwards of a 30% increase in estimates (Hopper et al., 2008; Smith & Castaneda-Tinoco, 2019).

The present dissertation study used the definition of homelessness provided by the Health Resources Services Administration (HRSA) because the research partners' eligibility for services are determined by this legislation. HRSA states that an individual experiencing homelessness is "an individual who lacks housing (without regard to whether the individual is a member of a family), including an individual whose primary residence during the night is a supervised public or private facility that provides temporary living accommodations and an individual who is a resident in transitional housing." (2018, Section 330(h)(5)(A)). This definition is more inclusive than The U.S. Department of Housing and Urban Development's (HUD) conceptualization of 'literal homelessness,' which is limited to shelters and missions, time-limited supportive housing designed to transition people into permanent housing units, unleased short-term housing such as single-room occupancies (SROs), hotels and motels, and unsheltered settings such as streets and parks, vehicles, abandoned buildings, and tent encampments (National Healthcare for the Homeless Council, 2021). HRSA's definition includes supervised facilities that provide temporary living accommodation such as for people exiting incarceration or treatment from psychiatric, substance abuse recovery, or medical systems without housing plans (HRSA, 2022).

HRSA's definition of homelessness also includes those who experience *housing precarity*, also referred to as the 'marginally-housed' or the 'hidden homeless' (James et al., 2020). Housing precarity refers to a risk of imminently losing housing, usually driven by both social and economic factors (Gonyea & Grenier, 2021) -- individuals who are sheltered in a place sanctioned as appropriate for housing, but under circumstances that could easily render them literally homeless. An essential quality of housing precarity, or precarity of other material resources, is that it produces exploitation and coercion (Millar, 2017). Such circumstances include those living in permanent housing but facing eviction, foreclosure, or condemnation; couch-surfing or sleeping doubled-up rent-free (National Healthcare for the Homeless, 2021). Other catalysts for housing precarity can include interpersonal factors such as abuse and violence (O'Campo et al., 2016) or familial estrangement or exile (Fine et al., 2018). Precarity may also be prompted by environmental factors such as climate change (Bezgrebelna et al., 2021; Kidd et al., 2021) or generational housing norms shaped by economic and cultural trends (Owens & Green, 2020).

Demographic Characteristics of U.S. Homelessness

Race. Black and Indigenous people disproportionately experience homelessness across all age groups due to structural racism embedded in housing policy, land use, and privatization efforts (Olivet et al., 2022). While numerically, white people are the most represented group among those experiencing homelessness, Native Hawaiian and other Pacific Islander, American Indian/Alaska Native, and Black populations have the highest rates of homelessness in the United States (Coalition to End Homelessness, 2021).

Gender, gender identity, and sexual orientation. Cisgender men comprise 70% of the U.S. homeless population (Coalition to End Homelessness, 2021). LGBTQ adult homelessness has been remarkably understudied (Ecker, Aubry, & Sylvestre, 2019). Cities such as San Francisco, Seattle, and Austin that ask about sexual orientation and gender identity in their Point in Time counts have found high rates of LGBT adults experiencing homelessness, but because of their reputations as sites of queer migration, may not accurately represent national rates and disparities (Romero, Golberg, & Vasquez, 2020). In a population-based study of homelessness among young adults, LGBTQ people experienced homelessness or housing precarity at double the rate of their cisgender and heterosexual peers (Shelton et al., 2018). Transgender adults likely experience higher rates of homelessness than their cisgender LGB peers, with an estimated 12% of transgender adults experiencing homelessness within the past year (James et al., 2016). In this same study, over half of transgender women and femmes who identify as AIAN, Black or multiracial reported homelessness within the past twelve months (James et al., 2016).

Disability and neurodivergence. Approximately half of all people who experience homelessness in the United States have a documented disabling condition (HUD, 2020). Very little attention is paid to whether these disabling conditions are congenital or acquired, at what point in one's housing trajectory they manifest, or how unhoused people self-identify or relate to diagnoses (Manthorpe et al., 2019). In a group of adults experiencing homelessness, 34% surveyed identified disability, physical health, or mental health issues as the cause/s of housing problems (Barile, Pruitt, & Parker, 2017). Risk of homelessness in one's lifetime is significantly increased among those with autism (Churchard et al., 2019), intellectual disabilities (Brown & McCann, 2021), traumatic brain injury (Cusimano et al., 2021), or attention-deficit/hyperactivity disorder (Murillo et al., 2016). Serious mental illnesses such as schizophrenia and bipolar disorder are also associated with risk of homelessness (McGuire et al., 2021).

National origin and citizenship status. Immigrants experiencing homelessness are more likely to be disabled, heterosexual, and married than native-born people who experience homelessness, and are less likely to have a history of mental illness or substance abuse, incarceration, or past military service (Tsai & Gu, 2019). While U.S. immigrants are not more likely to be homeless than native-born adults (Tsai & Gu, 2019), their findings illuminate the relative precarity that immigrants face without the intersectional barriers faced by other unhoused populations. Undocumented day laborers who have lost economic stability from occupational injury or health events are a subgroup of emergency shelter users and unsheltered campers (Seixas et al., 2008), a group with unique access barriers to housing assistance and supportive housing placement (Shier et al., 2016), and a group experiencing economic and geographic precarity (Chacko & Prince, 2021). The COVID-19 pandemic's impact on labor opportunities, border enforcement, travel and transportation provided additional economic and social precarity for migrant workers, immigrants, and refugees (Briggs et al., 2021).

A caveat on demographic measurements. Current strategies for quantifying and measuring homelessness may lead to underestimating the intensity of housing disparities between demographic groups. For example, older women experience housing precarity at a higher rate than younger women (Richard et al., 2022). Latinx, Asian, and Pacific Islanders are also more likely to double up than white people, perhaps due to a combination of mutual self-reliance within culture and community, but also due to underutilization of formal assistance (Aiken, Reina, & Culhane; 2021). Ruiz & Contreras (2020) suggest that for older and unhoused Latinx men in the United States, ageism amplifies long-term barriers to economic and residential stability, such as forced migration and political displacement, migratory work histories, labor exploitation, xenophobia, and language bias. Rural people are more likely to be determined as marginally-housed or housing-precarious given differences in housing supply, public geographies, and the invisibility of low-density housing (Petersen, 2020). LGBTQ adults may be overrepresented in the “hidden homeless” due to fear of discrimination, harassment, or violence in the shelter system (Ecker, Aubry & Sylvestre, 2019), as well non-kinship relationships fostered within queer and transgender communities that may offer access to informal housing assistance (Harner, 2021). LGBTQ people and cisgender women are more likely than heterosexual cisgender men to exchange sex for basic needs like shelter, which may contribute to underreported prevalence of women and LGBTQ homelessness (Fraser et al., 2019). In localized studies that test more inclusive measurement strategies than the Point in Time count, the previously-uncounted subset of the sample had higher rates of people of color and women (Smith & Castaneda-Tinoco, 2019).

Older Adult Homelessness

Over half of the single adults experiencing homelessness are over 50 years of age, and the number of unhoused people over 50 years of age is predicted to increase three-fold by 2030 (Culhane et al., 2019). Both chronic homelessness and first-time experiences with homelessness among older people are predictors of the emergence of chronic health conditions (Brown et al., 2019) as well as heightened psychosocial-emotional distress (Bullock-Johnson & Bullock, 2020). Health and homelessness have a bidirectional causal relationship as well— illness and disability may decrease income opportunities for households and generate exorbitant expenses in the current healthcare payment system (Almgren & Lindhorst, 2011). Population-based samples have found that relocation costs and delinquent housing payments are associated with poorer health (Bergard et al., 2012; Singh et al, 2019). Lichtenstein (2017) found that since the Great Recession, foreclosures among older homeowners were commonly preceded by recent familial deaths and medical debt.

A review of older adult homelessness literature (Grenier et al., 2016) states that existing research has aimed to understand the prevalence of homelessness among age cohorts and sociodemographic groups, examine existing housing options for low-income older adults, and interrogate resource allocation and implementation of interventions aimed at addressing the needs unhoused older adults. Racism, classism, ableism, homophobia, xenophobia, and other systems of oppression play a role in perpetuating homelessness among systemically-marginalized older people (Grenier et al., 2016). For example, older people experiencing homelessness report racial discrimination (Paul et al., 2020), displacement and overcrowding due to gentrification (Handley et al., 2022), changes to social role and community membership (Gonyea & Melekis, 2016), loss of autonomy (Odgen, 2014), and threats to spiritual, social, and emotional wellness (Moxley, Washington & Calligan, 2012). Aversion to institutionalization and anticipatory grief related to potential re-institutionalization also shape the geographies of older adults experiencing homelessness (Johnson, 2022). However, there is a gap in sufficiently understanding these differences and how they are related to different housing and healthcare needs (Finlay et al., 2018).

In a review of available literature, Klop et al. (2018) identified place-based concerns of unhoused palliative care patients such as being transferred into institutional care, inability to enact care preferences, dying alone, being unidentified after death, lost privacy, and losing familiarity with their surroundings. Klop et al. (2018) also noted some preferences that may be moderated by environment, such as a higher likelihood of wanting resuscitation and life-sustaining treatment. Perspectives of homeless older people on later-life and end-of-life care decision-making have indicated challenges to planning for anything outside of immediate concerns (Stajduhar et al., 2019). Hubbell (2017) found other concerns of dying alone, unnoticed, or unidentified, and worry about mass burial without funeral or other after-death consequences. Spiritual care, authentic provider-patient relationships, comfort, and autonomy have been identified as important to unhoused people during their end-of-life experiences (Webb et al., 2020). Research indicates that health and social service providers (Ko & Nelson-Becker, 2013) are frequently involved in the end-of-life planning for unhoused older adults with serious illness. Specific types of providers, such as inpatient psychiatrists (Shalev et al., 2020), chaplains (Chang et al., 2012), and social workers (Davis-Berman, 2016), have been identified as key players in coordinating interdisciplinary care to align with client's needs and wishes. There are few curricular requirements (Iles-Shih et al., 2011), training opportunities (Jego et al., 2018), or workplace supports (Wirth et al., 2019) for professionals providing holistic healthcare to homeless populations.

The Housing Care Continuum

Coordinated Entry

The Homeless Management Information System (HMIS) was created in 2004 to produce a nationwide unduplicated account of people experiencing homelessness, including names, social security numbers, household identification numbers, and demographic variables (HUD, 2021). The current measurements used to count homelessness are part of a governmental mobilization to 'end' homelessness, a framework that requires a narrow operationalization to make achieving a 'functional-zero' homeless population realistic (Evans & Baker, 2021). In addition to these operationalized variables aiding in the monitoring and surveillance of people in poverty over time (Gilman & Green, 2018), they serve as a tool of abstraction that allows the housing care continuum to manage homelessness without considerations to how intersecting racism, xenophobia, ableism, classism, homophobia, sexism, and transphobia create and maintain homelessness and housing precarity (Willse, 2015). The consideration of disability is particularly pertinent. Those administering homeless or housing services define a "homeless individual with a disability" as:

> "(1) a disability as defined in Section 223 of the Social Security Act; (2) a physical, mental, or emotional impairment which (a) is expected to be of long-continued and indefinite duration, (b) substantially impedes an individual's ability to live independently, and (c) is of such a nature that such ability could be improved by more suitable housing conditions; (3) a developmental disability as defined in Section 102 of the Development Disabilities Assistance and Bill of Rights Act; (4)

> the disease of acquired immunodeficiency syndrome or any conditions arising from the etiological agency for acquire immunodeficiency syndrome; or (5) a diagnosable substance abuse disorder” (HUD, 2016).

The function of assessing disability within chronic homelessness is to determine *vulnerability*, which is a measure of capacity—who is currently able or predicted to soon be able to get themselves out of homelessness. In 2014, federal legislation supported the creation of a universal assessment tool, the Vulnerability Index-Service Prioritization Decision Assistance Tool (VI-SPDAT), to coordinate entry to housing services, which reached its full roll-out in 2018. The VI-SPDAT continues to be implemented by many communities to prioritize need when demand for housing outweighs supply (Balagot et al., 2019), through a series of questions that sort and categorize people based on how capable they are of exiting homelessness without government housing assistance. The VI-SPDAT, now in its third iteration, is being phased out of use in all communities (OrgCode, 2022) because of noted disparities in placement across race and gender lines (Cronley, 2020) and its shortcomings in acknowledging complexities such as domestic violence (McCauley, Reid & Sullivan, 2020) and underreported or unassessed medical conditions (King, 2020). It was still being used by Seattle at the time this study was conducted.

The Spectrum of Housing Care Options

Continuity in who provides care, where care is provided, and how much care is given is essential for patients to receive treatment aligned with their personal goals and wishes (van Walraven et al., 2010). Continuity in all aspects of life is threatened by the systems-level abuse and neglect inherently embedded within the experience of homelessness (Maidment, 2006). Appendix A provides a general overview of housing care options in the United States, as well as adjacent locations that are regularly frequented prior to, during, and/or after accessing housing care. An assumption inherent to the research aims at hand is that there is a hierarchy among these housing care options in what is acceptable, preferable, and feasible for palliative care patients experiencing homelessness or housing precarity.

Permanent housing. Supportive housing offers affordable housing, often studio apartment units, with on-site support services ranging from health and mental health care, case management, substance abuse recovery, and education and employment readiness (Corporation for Supportive Housing, 2022). Initiated by the psychiatric consumer, survivor, and ex-patient (c/s/x) movement, supportive housing started with acquiring single-room occupancies and other forms of housing and equipping them with peer support, with the goal of community integration (Ben-Moshe, 2020). Supportive housing eligibility and offerings are dictated depending on their funding source and span a range from scattered-site single apartments with monthly or semi-annual check-ins, to buildings with 24/7 staffing and co-located clinics or day programs. Rights of supportive housing tenants also vary from state to state (Korman, 2007). Supportive housing is associated with improved self-rated health (Rhoades et al., 2019) and reduced hospital visits (Rog et al., 2014).

A different model than permanent supportive housing, supported housing is a term used to refer to reduced-cost independent housing that allows for visiting services and intentional social programming, involves holding a lease, and is intended for long-term stay. This model includes low-income public housing, housing vouchers or subsidies, and naturally-occurring retirement communities (Tabol, Drebing, & Rosenheck, 2010). Public housing service delivery has shifted in the last decades to prioritize market-driven models, where subsidies like Section 8, HOPE VI, and Low-Income Housing Tax Credit (LIHTC) have aimed at giving low-income people access to the private rental market (McFadden & Lucio, 2014). Gentrification and urban development have created soaring rent prices and diminished low-income housing supply, placing older and disabled renters at risk for not finding appropriate housing and for facing displacement when their health or social needs change (McFadden & Lucio, 2014). Single-site public senior housing has continued through mechanisms like Section 202 and Section 811 (HUD, n.d.), and may even provide assistive services and health and social programming (HUD, n.d.). However, demand for such housing outweighs supply, with only 34% of income-eligible seniors in the United States receiving rental assistance for which they qualify (Couch, 2017).

Temporary accommodation. Temporary accommodation includes single-room occupancies (SROs), hotels, motels, accessory dwelling units (ADUs), couch-surfing/doubled up or another informal temporary arrangement, or transitional or time-limited housing intended to support a transition to permanent housing (HRSA, 2018). Single-room occupancies, also known as extended-stay hotels or residential hotels, have been essential housing options in the United States since the late 1800s, often intended for laborers, immigrants, veterans, and other subpopulations of the working poor (Sullivan & Burke, 2013). SROs are most frequently sparsely furnished 150-200 square foot rooms in densely packed corridors with a shared bathroom; they vary in price and amenities, with more expensive rooms having personal sinks, hot water access, and personal kitchenettes or communal kitchen space (Groth, 1994).

Tiny Villages are a collection of micro-dwellings with some on-site support. They are often constructed out of wood and weatherproofed for outdoor installation, with enough interior room for personal storage and a bed. The dwellings, or “tiny homes,” are sometimes equipped with wheels and easily disassembled and reassembled to aid in relocation. Tiny Villages are commonly assembled as several clusters of ADUs surrounding a centralized trailer that is equipped with hygiene facilities, a shared kitchen, and management offices (Heben, 2014). The Tiny Village model offers low-barrier temporary housing—they often are designed to serve those with barriers to shelter care, such as different-sex couples, people actively using drugs, people with pets, and those who avoid indoor congregate settings for personal safety or health concerns (Wong et al., 2020).

An emergency shelter is a temporary place designated for homeless or otherwise displaced persons to sleep, that does not require occupants to sign a lease or other agreements (HUD, 24 C.F.R. 576.2).

Healthcare institutions. Residential long-term care can include continuing care retirement communities (CCRCs), assisted living programs, skilled nursing homes, and group homes (National Institute on Aging, 2017). Options most commonly available for older people and families with less financial resources are adult family homes (AFHs) and skilled nursing facilities (SNFs), as payment models for other types of long-term care are often exclusive to those with assets and private insurance (Huffman & Upchurch, 2018). Adult family homes, also known as group homes or adult foster care, are independently-owned and operated community settings that can house up to eight residents and provide 24-hour staffing and assistance with daily living (Adult Family Home Council, n.d.). While licensed on a state level, these homes can determine their specialty, capacities, and admission criteria (Adult Family Home Council, n.d.). Skilled nursing provides both short-term rehabilitative services aimed at transitioning someone to a less acute care setting, and long-term custodial care for those who may not be able to live independently without medication management, wound care, or assistance with activities of daily living (National Institute on Aging, 2017).

Safety net hospitals vary in characteristics, but most commonly are defined as healthcare centers designed to serve poor communities, providing Medicaid-covered and uncompensated care to groups who are medically underserved (Almgren & Lindhorst, 2016; Hefner et al., 2021). While hospitals are intended for acute medical care, unhoused people have more frequent and longer hospital stays than demographically similar domiciled peers (Wadhera et al., 2020). Particularly among those with ‘tri-morbidities’ of mental illness, physical illness, and drug and alcohol use, hospital patients experiencing homelessness can experience barriers to safe discharge that can result in weeks or months in the hospital (Cornes et al., 2017).

Street response & carceral systems. Older adults may also be living unsheltered in a place deemed unsuitable for human habitation. Such places include vehicles whose locations are not permitted for residence, public transportation and park areas, or tent encampments. In the city where this study took place, there are both sanctioned encampments that have temporary permits and areas of unsanctioned encampments. Formal care providers that interact with those experiencing street homelessness include outpatient clinics that accept public insurance and are near homeless services (White & Newman, 2015), mobile health programs and street outreach (Yu et al., 2017), and first response teams such as paramedics, law enforcement, and fire departments (Hector & Khey, 2018). Those who are unsheltered are often interacting with surveillance and criminal punishment systems, particularly in an era of public policy that supports transcarceration— the blurring between care systems and carceral systems (Maidment, 2017). People in homeless care systems are therefore accessing healthcare embedded in correctional spaces such as jails (Chodos et al., 2014). Long-term residential substance abuse treatment programs are transitional spaces that may be accessed as a mandated alternative after release from jail or prison, or after an accumulation of documented legal encounters involving alcohol or drug use in public space (DeMatteo et al., 2013). Those in residential treatment programs have health and housing barriers both upon entry and in residential treatment aftercare (Manuel et al., 2017).

Housing Care Continuum Responses to Population Aging

Unhoused older adults conceptualize “bad deaths” as death from accident or violence, dying alone, prolonged life supports, and dependence during illness (Ko, Kwok, & Becker, 2015). Kaplan et al. (2020) has suggested that unhoused patients may benefit from tailored approaches to advance care planning that consider more urgent day-to-day concerns for survival, family trauma and unique kinship relationships, and the role of substance abuse and mental illness in pain management and treatment options. The growth of both homelessness nationwide and the concentration of homelessness among older adults has forced city, state, and federal homelessness response to turn its attention to supporting the most-marginalized older adults in “aging in the right place” (Sixsmith et al., 2019; Canham et al., 2022). However, little has yet to been done to develop and adapt interventions that specifically attend to the needs of older people at risk for experiencing homelessness, housing precarity, and displacement (Torres-Gil & Hofland, 2012).

Scholars have recommended specialized health care within permanent supportive housing (Shulman et al., 2018) and customized, flexible services that allow for an appropriate level of care in a comfortable environment (Davis-Berman, 2016; Klop et al., 2018). Programming interventions within supportive housing have been launched to increase wellness among older adult residents, including John Hopkins' Community Aging in Place Advancing Better Living for Elders (CAPABLE) program (Pynoos et al., 2018), the Hearth Outreach Program (Brown et al., 2013), and The Bridge's MAGIC framework (Heller, Gresko, & James, 2021). To encourage the development of specialized programs for older tenants such as these, the Corporation for Supportive Housing (2016) has developed a toolkit to support healthy aging. There are limited data on healthcare utilization within palliative care programs based in shelters and supportive housing settings, but there is preliminary evidence that they are cost-effective and successful at reducing emergency room usage (Podymow, Turnbull, & Tadic, 2006; McNeil, Guirguis-Younger, & Dilley, 2012). Shelter-based palliative care could offer the potential to extend a patient's connections with informal networks and significant places, though acceptance among staff and residents and feasibility regarding shelter staff's capacity to support care needs were identified as barriers to implementation (Sumalinog et al., 2016).

Testing and translation of these programs have been notably limited. Further, existing programmatic recommendations have largely been formulated with consideration to the material aspects of residences (accessibility, privacy, safety) and the human services available on-site. Research with housed older adults has strongly demonstrated the importance of subjective elements of place in older adults' quality of life (Buffel et al., 2014; Phillips et al., 2011), but these important considerations for unhoused patients have received little attention in recommending and designing housing and health interventions. The existing services are mostly fixed in location and have a limited ability to accompany patients across their end-of-life care trajectories.

Motivation for the Study

I would like to situate myself in relationship to the research topic and study participants. Reflexivity allows an audience to decipher how my personal and professional experiences may inform my frameworks, line of question, data collection, and analysis (Morgaine, 2017). I do this in narrative form, as critical queer and crip theorists encourage, to move beyond simply naming identities and toward a thorough examination of motivation, perspective, and goals (hooks,1989; Johnson & McRuer, 2014).

I am the adult child of two Early Boomers who both have experienced mental illness and substance abuse. My father experiences mania-induced psychosis, which wasn’t publicly visible until later in his life. Shortly after his retirement and an orthopedic surgery, he brought a gun to his former supervisor’s lawn uninvited in the night. Law enforcement peacefully apprehended him, and he was assigned to assertive community treatment. My mom is the poster-woman for reinventing oneself in later life and is now in recovery from alcohol abuse. While she was caring for and housing her older sister, she was arrested on a DUI charge. She was court ordered to attend intensive outpatient treatment, and a breathalyzer was required to start her car. She did not have the lung capacity to activate the engine, so neighbors and family shuttled her to mandated treatment nearly one hour away, assisted with my aunt’s needs, and helped run errands. These experiences with my parents have sensitized me to the disconnections between aging services and mental health and recovery worlds—in both crises, there were no clear articulations of how aging was a catalyzing factor, nor were there adequate services and responses that accommodated age-related needs.

I experienced a three-month episode of homelessness in the summer between my junior and senior year of college. I had been working at an assisted living community as a dining room attendant, and a nurse's aide, and it was not enough to support my housing expenses, so I decided I would live out of my car. I crashed on couches or parked in the driveways of friends, friends of friends, or parents of friends. Other nights, I rented a campsite. The nurses' aide manager let me shower at work in the respite apartment we reserved for visiting families, which sadly, was almost always unoccupied. Precarity was familiar to the other staff-- when other aides discovered where I was staying, I was invited into their personal narratives about addiction, family violence, and rural poverty.

While this moment was a blip in my life, experiencing homelessness while simultaneously providing elder care work reinforced ableist, ageist, and homophobic messages I already internalized about my own potential and legacy. For years, I lived in horror that I was going to "go crazy," go broke, and die alone in institutional care. At the time, it felt like a deeply singular experience, even though psychoanalytic circles have been discussing annihilation anxiety for decades (Kohut, 1971; Gediman, 1983). Psychic uncertainty and a heightened sense of responsibility are trademark experiences among children of parents living with serious mental illness (Foster, 2010), and these experiences can promote fears about personal capacity in early adulthood (Kallquist & Salzmann-Erikson, 2019). Fears of dying alone in institutional care are prevalent as we age (Riedl, Mantovan, & Them, 2013), and are particularly prominent among people in historically marginalized groups (Depaola et al., 2003) including LGBTQ people (Kortes-Miller et al., 2018).

In my first eight years as a social worker, I worked with older adults across New York City in a variety of settings: older adults' private homes, the homes of their adult children or other family members, community centers, clinics, halfway houses, residential drug treatment, skilled nursing, hospitals, homeless shelters, park benches, and more. The experiences of older people I encountered professionally were remarkably different than my family's experience. In our worst moments, my family and I have been shielded by racial privilege, educational attainment, socioeconomic status, and geography. My dad, my mom, and my aunt could have easily lost housing, faced more extreme punishment, or been forced into institutional care had it not been for racial and socioeconomic privilege and resourced informal care networks. Like most homelessness in the United States, my own homelessness was brief and temporary (Rankin, 2021). My housing precarity was truncated by my educational and financial access, and the intersectionality of my whiteness, my youth, and my presentation as nondisabled, all of which allowed me to be perceived as "student" rather than "homeless" in the places I lived. I did not encounter a police officer during the three months I was unhoused, nor did I access formal housing or shelter services.

My social work education did not prepare me to defend myself against the demands of the institutional settings I worked for and moved through. My job as a social worker was to respond to the requests of these settings to institutionalize, and implicitly to paternalize and gatekeep on their behalf which created great dissonance for me. My shock was a product of my naivete and privilege. Queer theorist interpretations of necropolitics (how sociopolitical violence, exploitation, and subjugation impose mortal danger and gradual/persistent dying [Berlant, 2007]) have noted how privileged queer people can be lured into enacting state violence with the false promise of safety and security (Lamble, 2014). I had been invited into the “fold of the state” (Agathangelou et al., 2008) to “care” for older adults. People at parties heard about my job and told me how noble I was and thanked me for my service. Other white queer people noted how dangerous it was for me to go into public housing, or more broadly, in neighborhoods that were poor and predominantly Black or Latinx. Ahmed (2004) notes that the enticing riches of this “affective economy” seduce us into aiding and abetting the nation-state in enacting and perpetuating marginalization. Being perceived as a martyr has social clout and political power; it also produces an othering in the work and in the world.

The assumptions in these statements I heard from others about my work were trifold—first, that it is a personal sacrifice to provide care. Aging and disability scholars have long challenged the ideas that care ‘recipients’ are the only beneficiaries of care partnerships (Lloyd, Patterson & Meurs, 2016); I was a beneficiary of my clients’ life stories, jokes, recipes, love and positive regard, and trust, to list a few. To frame care as a sacrifice is to also imply that some people are exempt from creating collective care and access for our shared communities (Piepzna-Samarasinha, 2019). Care workers are predominantly women of color, many of whom are immigrants (Poo, 2015); as a U.S.-born and male-assigned white person, I am not expected to participate in something so socially and economically undervalued – I was cast as making a sacrifice by doing so.

The second assumption is that my sacrifice was for the people at parties and not for my clients—that I should be thanked and socially rewarded for working with (managing and controlling) people who have been deemed disposable by the nation-state, who cause woe for taxpayers. Care often masquerades as the "indefinite confinement, forced extraction from communities and families, and removal of one's right to self-determination" (Eales & Peers, 2020, p. 1). The conceptualizations of race, madness, disability, class, and gender determine who is deserving of care (Mitchell, 2015). The nursing home is a prime example of the interweaving of these various identity ideologies. The original nursing home was developed at the turn of the twentieth century by Christian white women as a distinct space for white and Christian older people to be 'rescued' from the dangers of the almshouses, where adults of all kinds deemed unsuitable for work were warehoused (Boodman, 2019). Receiving this messaging about providing mental health care to poor older adults of color presented a cognitive and emotional dissonance when held simultaneously with the proclaimed values of social work to challenge colonial and racist notions of saviorism.

Third is an inherent assumption that I, along with all white queer people, have rights to public safety that justify the surveillance, policing, or displacement of poor people of color (Hanhardt, 2013). Municipal remapping efforts have indeed generated shifts in neighborhood commerce, interpersonal networks of care, architectural landscapes, and urban policing with the political support and investment from prosperous, mostly white gay people invested in homonormative goals (Manalansan, 2005). Honoring a commitment to solidarity and action efforts across racial, socioeconomic, geographic, and generational lines means maintaining a willingness to transcend spatial norms. Shaping our cities to be safe and affirming for queer people will require abolitionist and anti-capitalist strategies that will also curb the policing and displacement of poor people, people of color, and disabled people.

Liberatory social work can be understood as refusal of this invitation into the "fold of the state." Refusal not only means saying no—it is the idea that we can generate new affiliations and responsibilities by setting limits (McGranahan, 2016). Refusal stands apart from political resistance in that refusal aims to reconfigure hierarchical power relationships instead of defying them, allowing willful hopefulness and a collective vision of futurity (Simpson, 2007). Refusal can be spatialized, as it can mean a commitment to traversing literal and metaphorical borders created by conceptions of belonging, identity, and political motive (Anzaldúa, 1987).

Just prior to pursuing a doctorate, I developed and led an interdisciplinary aging-in-place program within supportive housing. Our team-- a nurse, a peer specialist, a case manager, and two MSW students-- aligned with the initial vision of supportive housing as a consumer-led effort against the institutionalization and systemic neglect of those with mental health diagnoses, addiction histories, and experiences with homelessness and housing loss (Ben-Moshe, 2015). Our responsibility was to the tenants and their health and housing goals. We related to them as experts on their own aging, and advocated on their behalf with doctors, nursing home staff, and our own supportive housing colleagues to imagine safe, fulfilling, and desirable later-life experiences.

Atul Gawande (2014) states, "you'd think we would have burned the nursing homes to the ground. We haven't, though, because we find it hard to believe that anything better is possible for when we are so weakened and frail that managing without help is no longer feasible. We haven't had the imagination for it" (p 79). I now see my journey in social work as moving toward a refusal of (re)institutionalization as the best option for older adults facing intersectional systemic vulnerabilities. My line of research is a commitment to developing our collective imaginations for alternatives and realizing them. I do not in any way claim insider identity in research with older adults experiencing homelessness or their kin, given how the intersections of race, class, age, geography, and health status dictate how homelessness is experienced. I am, however, a queer, mad caregiver, and social worker. I find joy and communion in considering refusal as a potential path to become old in ways that prove my fears wrong and to offer that to others.

Significance & Purpose of the Study

Significance & Aims

Public hospital systems are increasingly investing in outpatient and community-based palliative care (Smith et al., 2013), and home and community-based aging and disability services (HCBS) are also increasingly common (Harris-Kojetin et al., 2016). The drastic changes made to de-congregate emergency housing during the COVID-19 pandemic have spurred consideration for permanent changes that can be made to enhance health in temporary shelter accommodations (Bodkin et al., 2020; Johnson et al., in press). Similarly, healthcare's COVID response has sparked recognition regarding healthcare disparities and social determinants of health (Rollston & Galea, 2020), as well as contemplation surrounding the intent and implementation of past policies and procedures (Etkind et al., 2020). This dissertation focused on the basic research information needed to advance translational efforts toward mobile treatment and residential programs for seriously ill, unhoused older adults. I aim to inform direct practice in multiple service sectors, including the housing care continuum, palliative care organizations, and aging and disability services.

Housing justice must be seen as an essential aim of critical aging and disability scholarship. There is window of opportunity to generate knowledge and realist suggestions for best addressing the needs of older adults living unsheltered and throughout the housing care continuum. To successfully develop & adapt hospice and palliative care models for patients experiencing houselessness or for those living within the housing care continuum, it is essential to understand the how barriers manifest in care and impact end-of-life care trajectories. This dissertation was guided by two main aims: (1) to characterize the disparities between desired and actual place of care experienced by unhoused older adults facing serious illness; (2) to illustrate how healthcare and housing systems respond to the needs and wishes of people facing housing precarity and homelessness at end-of-life.

Dissertation Overview

In the second chapter, I review extant literature on the production of disability, serious illness and end-of-life and its relationship to the study of place in gerontological and health science literature. In the third chapter, I describe the research partnership with a novel homeless palliative care team at the heart of this study. Alongside the introduction to the community partners who assisted in the study, I present the mixed-method approach taken in answering the overarching research questions.

In Chapter 4, I present findings that highlight the barriers and opportunities in systems of care for older adults experiencing homelessness through a grounded theory of health and social service providers across sectors. The results highlight how provider experiences can inform future efforts for housing and healthcare intervention with those aging while experiencing homelessness. I interviewed 30 healthcare and social service providers working across various systems of care about barriers and opportunities for change in permanent housing, temporary accommodations, healthcare institutions, and carceral systems. My research questions were: (1) what are provider perceptions of the barriers to working with unhoused older adults across housing and healthcare systems? and (2) what opportunities do healthcare and housing providers see in achieving patient-centered care for unhoused older adults?

No known research has yet to follow homeless palliative care patients across the last months of their lives to understand changes in their health and housing needs. In Chapter 5, I describe four common residential typologies derived from a chart-based study of 75 palliative care patients experiencing homelessness or housing precarity sampled from PCT rosters. The primary research question was: what are the locations of treatment and transitions in housing experienced by unhoused patients receiving palliative care?

In Chapter 6, I conclude the dissertation by considering the implications these findings within the service context provided through team observation and provider interviews. In these implications, I outline considerations for building capacity among health and social service providers, developing future programming, advocating for policy change, and embarking on needed research.

CHAPTER 2

LITERATURE REVIEW

The Sociopolitical Production of Illness, Disability & End of Life Care

Older adults comprise the most significant proportion of single adult homelessness (Culhane et al., 2013) and the number of older adults experiencing homelessness was predicted to triple by 2030, even prior to the COVID-19 pandemic (Culhane et al., 2019). These two facts are the foundation for the rationale of this dissertation study.

Emergent from Fanon's interrogation of colonialism and racialized violence (1961), necropolitics (Mbembe, 2003) suggests that dominant social and political forces dictate whose life matters which constructs the disposability of people both in a literal biological sense and more abstractly, through social and/or spatial exile. Through the lens of this framework, the government is responsible for the (re)production of illness, disability, and early death, and benefits from controlling those rendered Other by its policies (Puar, 2017).

Homelessness is widely understood as detrimental to health. In 2020 in Los Angeles alone, over 1,300 people died while experiencing homelessness (County of Los Angeles, 2021). U.S. media coverage of homelessness in the United States has warned of "medieval" diseases such as tuberculosis, typhus, trench fever, and shigellosis re-emerging in shelters and encampments (Summers & Theroux, 2021). In the emergence of the COVID-19 pandemic, people experiencing homelessness were again cast as vectors of contagion (Stevens, 2022). Public health risks (e.g., needles, feces, fear of violence) are often cited as reasons for municipal efforts to regulate and criminalize visible homelessness (Westbrook & Robinson, 2021), implying that the presence of the homeless is inherently deleterious to the health of communities. Regulatory technologies are justified through the logic of sparing citizens and frontline workers from potential threats to health and safety; for example, a robotic “dog” used for perimeter security between the U.S.-Mexico (Dormehl, 2020) was also deployed by the New York Police Department to collect facial recognition data during 2021 protests against racialized police violence (Yunus & Doore, 2021), and, ultimately, that same robot was used by the Honolulu Police Department during Covid-19 to scan unhoused people for higher-than-average body temperatures (Cole, 2022). Tools such as these aim to preserve *biosecurity*—the disarming of a perceived threat to public health by defining borders that have punitive consequences when breached (Hinchliffe et al., 2012).

American ideology has shaped public perceptions of homelessness as a personal flaw and visible expression of helplessness or criminality (Amster, 2008). The discrimination and stigmatization of people experiencing homelessness—homeism-- can stem from the meritocratic belief that those who become unhoused are at fault for their health and housing circumstances (Canham et al., 2021). This ideology is used to justify municipal, state, and federal policies that dictate where and by whom homelessness is experienced and witnessed (Herring, 2014). In a 2022 report on nursing home quality, the National Academies of Sciences, Engineering, & Medicine claimed that COVID simultaneously increased leniency for maladministration and increased demand for beds. Consequentially, numerous investigations since 2020 have identified unsafe transfer and eviction out of nursing homes and into homeless shelters to clear nursing home beds for more lucrative short-term patients (National Academies of Sciences, Engineering, & Medicine, 2022). This illustration highlights, perhaps to an extreme, how otherwise-homeless older adults are related to as surplus life when an opportunity for institutional profit avails. The everyday geographies of homelessness are shaped by when and for whom public sympathy is more exploitable for financial and political gain—for example, targeted and well-funded strategies to address homelessness among veterans or children, or carceral interventions to disperse street homelessness in the service of tourism or commerce (Bancroft, 2012).

Punitive policies and acts in healthcare institutions, housing care systems, carceral systems, and public neighborhood spaces enforce homelessness as a display of the disposability of human life (Speer, 2019). Such policies and acts of discipline in public institutions target people of color throughout the life course (Paul et al., 2019). Scholars have identified the presence and longitudinal impacts of racialized punishment in schools (Bacher-Hicks, Billings, & Deming, 2019), hospitals and healthcare clinics (Metzl & Roberts, 2014), residential care facilities (Onah, 2018), psychiatric wards (Metzl, 2010), substance abuse treatment (Kaye, 2020), prisons (Brewer & Heitzeg, 2008), shelters (Lyon-Callo, 2008) and in the street—for example, 55% of disabled Black people in the United States have experienced arrest by the age of 28 (McCauley, 2017). More than half of the people killed by law enforcement in the United States are disabled people of color, and in some instances, health and disability have been misidentified as the cause of death (Thompson, 2021). Structural violence frequently creates and permits interpersonal violence (DeVerteuil, 2015)— people experiencing homelessness are common targets of bias-motivated violence, and one in four attacks on homeless people result in death (Levin, 2020). Racialized disablement enacted and perpetuated by the nation-state (Puar, 2017) serves as an ongoing and accumulating barrier not only to secure housing, but also as a tool to limit spatial imaginations.

Serious Illness and End-of-Life

Serious illnesses are considered progressive medical conditions that will likely prompt irreversible decline (Hui et al., 2014). End-of-life processes may include decreased mobility, appetite, and consciousness; increased pain, discomfort, and agitation; and changes related to one's respiration, digestion, and sensory perception (Hospice Foundation, 2018). Advances in medical technology have prompted many to live longer with serious chronic conditions, which has, in turn, created a mismatch between healthcare consumer need and healthcare system capacity (Institute of Medicine, 2015). Experiences with and processes surrounding serious illness and end-of-life are not exclusively medical—services oriented to serious illness and dying take holistic approaches that include attention to one's social, emotional, and spiritual needs (Institute of Medicine, 2015).

Morbidity & mortality

Heart disease and cancer are the leading underlying causes of death in the United States (Ahmad et al., 2020). Chronic conditions such as emphysema, Alzheimer's-related dementias, diabetes, and kidney disease remain in the top ten leading causes of death (Ahmad et al., 2020), though eclipsed by COVID-19 death rates (Woolf, Chapman, & Lee, 2021). Almost 60% of adults in the U.S. experience multimorbidity or comorbidity, the presence of more than one medical condition at a time (King et al., 2018). The prevalence of cognitive decline is linked to multimorbidity (Taylor et al., 2020) and a likely contributor of rising rates of accidental death, injurious falls, and drug poisoning among older adults in the United States (Dellinger & Baldwin, 2018). Illness trajectory can influence place of care (Murray et al., 2005)—for example, diseases like cancer that typically have short periods of evident decline and diseases like dementia that involve prolonged decline are less likely to prompt death in the hospital than chronic cardiac, pulmonary, hepatic, or renal diseases (Hicks et al., 2018).

Inequities in morbidity & mortality

Mortality rates for all racial and ethnic groups in the United States have been on the rise, but Black and Latinx mortality rate are rising at greater pace, contributing to the already existing racial/ethnic disparities in death (Luck et al., 2021). Multimorbidity development and chronic disease accumulation among midlife adults and older adults is both more common and more likely to be burdensome among Latinx and Black Americans than white Americans (Quinones et al., 2021). Among those who die of chronic illness, being white and married/partnered are primary predictors of dying outside of the hospital (Hicks et al., 2018). Due to health disadvantages related to sexual orientation, lesbian and gay older adults have a higher likelihood of disability and increased risk for chronic cardiovascular, hepatic, and pulmonary conditions as well as diabetes (Cohran et al., 2016; Fredriksen-Goldsen et al., 2013). The presence of cognitive impairment (Ma, Chan & Carruthers, 2014), developmental disability (Landes et al., 2019), mental health condition (Scott & Happell, 2011), and physical impairment (Lunney et al., 2015) are all associated with increased risk for serious illness. People experiencing homelessness endure serious health conditions at three-to-six times the rate of their housing-secure peers (Patanwala et al., 2018). Unhoused people are more likely to experience complications from illness and die from conditions such as heart disease, cancer, lung disease, HIV/AIDS, and renal disease more easily treated among those with stable housing (Hwang et al., 2001). Morbidity and mortality rates among homeless populations are four to nine times higher than housed populations (Aldridge et al., 2018). The average age of death among people experiencing homelessness in the

United States is 48 to 52 years (Romaszko et al., 2017), a life expectancy 24-28 years less than the general U.S. population (Master, Aron, & Woolf, 2022).

End of Life Care Continuum

Hospice

Hospice care is focused on the holistic care of patients and their care network in the last days, weeks, and months of life. Physicians, nurses, health aides, social workers, spiritual care providers, rehabilitation therapists and volunteers assist with the comprehensive needs surrounding death and dying (National Hospice and Palliative Care Organization, 2022). Hospice care is most often delivered in the home but may also be a service provided while someone is in a hospital, skilled nursing facility, or adult family home (Kassam et al., 2014). While rare, there are also free-standing residential hospice centers (Kassam et al., 2014). For Medicare and most private insurance companies to cover costs of care, patients' illnesses must be diagnosed as terminal, and patients must opt out of curative treatments (Medicare.gov, n.d). While Medicare is the primary payer for hospice across the country, only 12-15% of Medicare beneficiaries receive hospice in their last year of life (Fine, 2018).

Palliative Care

The International Association for Hospice and Palliative Care (2018) describes palliative care as specialized health support for those with serious illness who are suffering. It involves interdisciplinary non-curative support to manage physical symptoms, identify patient or family-directed goals of care, and coordinate reassessment and action surrounding identified goals of care throughout one's illness trajectory. Unlike other interactions with medical systems of care, palliative care relates to healthcare as a vehicle for achieving patients' holistic personal goals (Kogan et al., 2016). Palliative care aims to build patients' and families' capacity for making personalized decision about life and care from diagnosis to death (IAHPC, 2018). The integration of palliative care into cancer care has been a major part of the evolution of oncology (Chow & Dhalin, 2018) and has led to increased attention to palliative care during the treatment of other serious chronic illnesses (Quinn et al., 2020).

Theorizing Space, Place & Home

Place is an important facilitator of quality of life in healthcare decision-making (Teno et al., 2004). Theorizations of "space" have typically referred to physical and measurable (i.e., material) geographies, while the term "place" in human geography has been used to describe the conceptual, symbolic, and emotional relationships (i.e., subjective) between a person and the physical environment (Tuan, 1977). Thrift (1999) asserted that places came into existence through interactions between human and non-human dynamic "actors." From this perspective, place is both the appearance or feel of a physical environment and the discursive, relational activity of how we co-exist within it (Forde & Magnussen, 2015). This relational turn in geography promotes the idea that place is non-static—that living and non-living components, humans included, shape and reshape place through our actions and activities (Ingold, 2000). Our shared meanings of place inform our interactions in and with them (Popay et al., 2003). Conversely, the relationality of place also highlights the potential discordance individual people and groups of people may have when making meaning of and use of a shared place (Shields, 1992).

Most often, *home* is indicated as the place palliative care and hospice patients wish to receive services (Bell et al., 2018). The concept of home, however, is one of vast symbolic meaning, cultural and geographic nuance, and personal subjective variation. I adopt an alternative notion of home as an ongoing negotiation and relationship to several places—places across spectrums of conventionality and desirability (Grenier, Barken & McGrath, 2016) in which one can strive toward various developmental tasks of later-life, such as agency, comfort, privacy, social connection, meaning-making, and acceptance (Burns, 2016). For example, one may conceptualize their home as an amalgamation of experiences living in an emergency shelter; interacting with friends, supports, and neighbors at nearby senior center; building a shelter from recycled pallet boards; being rooted in a particular city or nation or landscape; and reminiscing about past residences and formulating aspirational ideas of a future residence.

Therapeutic Landscapes

The desire for serious illness, dying, and death to occur at home raises theoretical questions as to how the therapeutic nature of place can shape the end-of-life care wishes for those who live outside of traditional housing. Theories of therapeutic landscape help to consider the interconnected physical, social, and symbolic components of our everyday geographies in our efforts to maintain health (Kearns & Milligan, 2020). Since the theoretical concept of the therapeutic landscape was first proposed (Gesler, 1993), it has been adopted across humanities and social sciences as a tool for understanding and illustrating how interactions with place influence perceptions of wellness, healing, and consequentially, of harm and exclusion (Kearns & Moon, 2002).

Healing aspects of place have been examined in sought-after locales like religious pilgrimage sites (Williams, 2010), natural settings (Kearns & Collins, 2000), healthcare institutions (Dunkley, 2009), and camps and spas (Hoyez, 2007). However, therapeutic landscape as an idea has been used to examine our relationships with everyday places over time. The constellation of public gathering places we access regularly, known as natural neighborhood networks, provide a container for developing community and attachment to place (Gardner, 2011). Localized inter-relationships between land, culture, history, and health shape what places accommodate and promote well-being (Marques et al., 2019). Comprehending oneself as a part of the ecosystem of a place can generate a rootedness (McIntosh et al., 2018). Changes in health can prompt new interactions and relationships to place over time (Meijering et al., 2016). Perceptions of accessibility and safety related to one's aging experiences can shift the meaning and therapeutic value of a landscape (Finlay et al., 2015). Perspectives on relationships with place in elderhood and later life have evolved into a dynamic understanding that both our bodies and our environments are in regular flux, often through sustained interaction of the two (Bigonnesse & Chaudhury, 2020). At end of life, relationship with place and land may hold spiritual significance or signify a loss or betrayal by one's community (Hutson, 2016). Hospice residents have described a process of adjusting to place—what begins as a sense of discontinuity in one's life after being placed in an unfamiliar setting can evolve into a positive re-engagement in the world due to purposeful and intentional interactions with and within the hospice residence (Moore et al., 2013).

Places culturally marked as healthy support normative stances on personal autonomy and decision-making as seriously ill people interact with their surroundings (Smyth, 2005). For example, seaside or pastoral countryside asylums were designed with healing landscape in mind, prompting people labeled as mentally ill or disabled to be forcibly separated from places and kinships of significance and detained (Park, Radford, & Vickers, 1997; Burch, 2021). Precarity shaped by racism, sexism, classism, ableism, and addiction stigma creates constrained options and opportunities for coercion; the imposition of this constraint or mandate can prompt entry into places deemed therapeutic by power structures (Love et al., 2012). Such spaces should be interrogated for their supposed ability to produce wellness outcomes.

Heavily stigmatized places that are considered sites of illness or un-wellness can hold significant healing value to those who create, utilize, and maintain the space (Mokos, 2017). In Brewster's (2013) study of homeless geographies, she discussed the therapeutic value of the public library as a source of comfort, empowerment, and familiarity, emphasizing its importance as a space not of service provision, but of agency and community integration. Mokos (2017) envisions the river-bottom encampment as a therapeutic landscape, noting that trickling water, tall vegetation, opportunities for human-wildlife cohabitation, and amount of undeveloped space provided river-basin residents with tranquility, privacy, independence, and meaningful social contact. Marks (2021) uses a bicycle workshop-based intervention to consider what non-medicalized 'enabling places' could offer for people experiencing homelessness, including skill building, task-oriented and non-hierarchical socialization, and opportunities to give back to the larger community. In an ethnographic study of the Venice boardwalk, Bignante (2020) illustrates the production of healing space through the emotional, social, symbolic, and spiritual exchanges of homeless street vendors. Through the examination of previously-unimagined applications of therapeutic landscape, this body of scholastic work prompts consideration of whose perceptions of health and healing are dictating our conceptualization of what is therapeutically valuable.

Space, Place & Home in Aging & End-of-Life Care

Aging in place, the idea of living in one's home and community for as long as possible, is upheld as the ideal in older adult policies and programs (Lehning et al., 2017) and patient perspectives alike (Wiles et al., 2012). Staying in one's historical place during later-life health events or functional changes can in fact preserve social and psychological belonging, offer accessibility and comfort that familiarity facilitates, and allow for autonomy and person-directed care (Narushima & Kawabata, 2020). Similarly, there are healthcare system processes and a dominant public opinion that reinforce the notion of “bad” places to die, such as emergency departments (McCallum et al., 2018). Home can be a safe place to die because it facilitates a connection to self and community, offers opportunities to direct care, and offsets potential for overwhelm and discomfort in dying processes (Rainsford et al., 2018). Choice in place of care has expanded for many community-dwelling older adults with a spectrum of health needs, as home and community-based aging and disability services (HCBS) are increasingly common (Harris-Kojetin et al., 2016), and public hospital systems are investing in outpatient and community-based palliative care (Smith et al., 2013) that may facilitate staying at home or in the care of family, friends, and/or community in serious illness and in dying.

However, a unilateral approach to seeing home as the optimal place of care has been critiqued. Feminist and disability scholars have questioned the universality of comfort at home, highlighting its significance for some as a place of sustained violence, power and control imbalances, isolation, and disconnection (Annison, 2000; Mallett, 2004). Williams (2002) discusses how shifts toward home and community-based healthcare service delivery may re-shape home and/or everyday geographies as a place of struggle for older and/or disabled adults. Golant (2015) has challenged aging in place as a universal strategy due to the disparities facing older adults in health, ability, social resources, and community contexts; in some instances, relocation may aid in comfort, agency, and independence and can be related to as resilience or an adaptive coping strategy to age- or health-related changes. Healthcare providers are faced with managing patient and family expectations of where care will be delivered throughout the entirety of the illness, which sometimes occurs over months through gradual decline punctuated with episodic increases in acuity, or gradually over the course of years in the case of chronic illness or advanced age (Munday et al., 2007). Inequities prevent these outcomes for many—social support, availability of home-based services, and access to palliative care predict the ability to receive serious illness and end-of-life care in one's preferred location (Burge et al., 2015). There are established barriers to palliative care and hospice services connected to racism (Johnson et al., 2020), classism and ruralism (Hutchinson et al., 2021).

Increasingly, healthcare systems have paid attention to the marketing of hospitals, nursing homes, and residential hospice through therapeutic design aimed at decreasing the institutional feel of end-of-life services (Duan et al., 2020). Palliative care and hospice have becoming increasingly flexible in design (Glenister, 2012) with multiple patient access needs in mind (Williams, 2017). Environmental changes in inpatient and residential healthcare settings have shown to increase recovery speed, activate health behaviors, increase appetite, and decrease patient and caregiver stress (Devlin & Andrade, 2017). Gardens are an increasingly prominent design intervention in hospitals, skilled nursing, and hospice (Sternberg, 2010). Gardens may facilitate reflective meaning-making processes and provide sensory grounding during end of life (Marcus & Sachs, 2014).

Restricted care choices among the estimated 12.2 million Americans who are uninsured, Medicaid-insured, or those dual-eligible for Medicare and Medicaid result in heavily-institutionalized experiences of later-life and end-of-life (Sharma et al., 2020).

While culture change in nursing homes is low overall, Black and Latinx older adults are less likely to have exposure to care settings engaging in de-institutionalizing practices (Chisholm et al., 2018). Affiliation, attachment, and aversion to place can be dictated by historical trauma, ancestral trauma, and collective intergenerational struggle (Dragojlovic, 2015; Gordon, 2008). Healthcare places where unhoused patients receive care reinforce social relations of power through the design of the physical environment--there is a history and memory of medical institutions that does not promote a "reputation for healing" insomuch as it does a reputation for harm, control, and exploitation (Giesbrecht et al., 2018).

Considering palliative care, hospice, and other end-of-life care within institutional healthcare and housing settings requires a careful consideration of perceptions of care. Places created to affirm the health and well-being of people experiencing homelessness, such as indoor drop-in centers (Johnsen, Cloke, & May, 2005), inpatient psychiatric care (Curtis et al., 2009), and outpatient mental health and substance abuse sites (Evans et. al, 2015) simultaneously offer formality and oversight that can provoke harm. This consideration requires assessing the spatial and temporal tensions between healthcare systems, their representatives, and patients, as the creation of caring and comfortable institutional space for people without access to other health-affirming places may instigate tension around length of stay and functions of space.

CHAPTER 3

METHODS USED IN DEVELOPING THE RASCAL-UP STUDY

The Research, Action & Supportive Care at Later-life for Unhoused Peoples (RASCAL-UP) Study was an exploratory mixed-methods study nested within the United States' only palliative care mobile outreach program for people experiencing homelessness. Primary data for this dissertation were collected through a community-engaged research collaboration with this team. The study was designed to answer a variety of research questions related to the lived experiences of unhoused people facing serious illness, the vast majority of whom were over the age of 50. The study drew from three major data sources: electronic medical records, observation of Palliative Care Team (PCT) meetings, and interviews with thirty service providers who partner with the PCT team across various systems of care. In this chapter, I detail the methods used in the creation of the RASCAL-UP study and the longitudinal database it has generated.

The acronym RASCAL-UP has symbolic meaning. The term rascal is likely a derivative of the Old French *rescaille*, meaning "outcast," and evolved through Middle English to *rascaile*, a "member of the lowest classes" or "one who scrapes [by]" (Cambridge English Dictionary, n.d.). Modernly defined, rascal can be used endearingly toward someone who is mischievous, or those whose behavior is disapproving but maintains likability (Cambridge English Dictionary, n.d.). Conjuring this term in the context of homelessness suggests moving beyond moral discourse surrounding homelessness and poverty, framing 'rascal' as a reclamation of dignity and humanity. Researchers and practitioners may also be rascals. Through observations and collaboration with providers, I have come to understand both their care work and our research endeavor as intentionally defiant of the healthcare system writ large, despite being a distant appendage of that system. In this way, these street-and-community-based providers and, by proxy, me as their researcher, were tasked with traversing both institutional and homeless life-worlds and functioned as outsiders in both. Our goal in this research endeavor was to trouble (or "rascal up") healthcare, housing, and social service systems to further consider the unaddressed needs of unhoused people experiencing aging, serious illness, and end-of-life.

The Carol LaMare Scholars in Oncology and Palliative Care Fellowship offered funding support for this study. Funding from the Sam and Bella Sebba Charitable Foundation aided in the dissemination of outcomes from the RASCAL-UP study. The author of the dissertation was the primary investigator and developed the study in partnership with practitioner-researchers Michael Light, Joseph Hufford, Anthony Boxwell, and Kelly Campbell. Dr. Taryn Lindhorst (committee chair) and Dr. Clara Berridge (committee member) provided supervision of the study, with additional consultation from Drs. Megan Moore (committee member) and Lynne Manzo (graduate student representative).

Overview of RASCAL-UP Study Methods

Epistemological Overview

Constructivist Grounded Theory

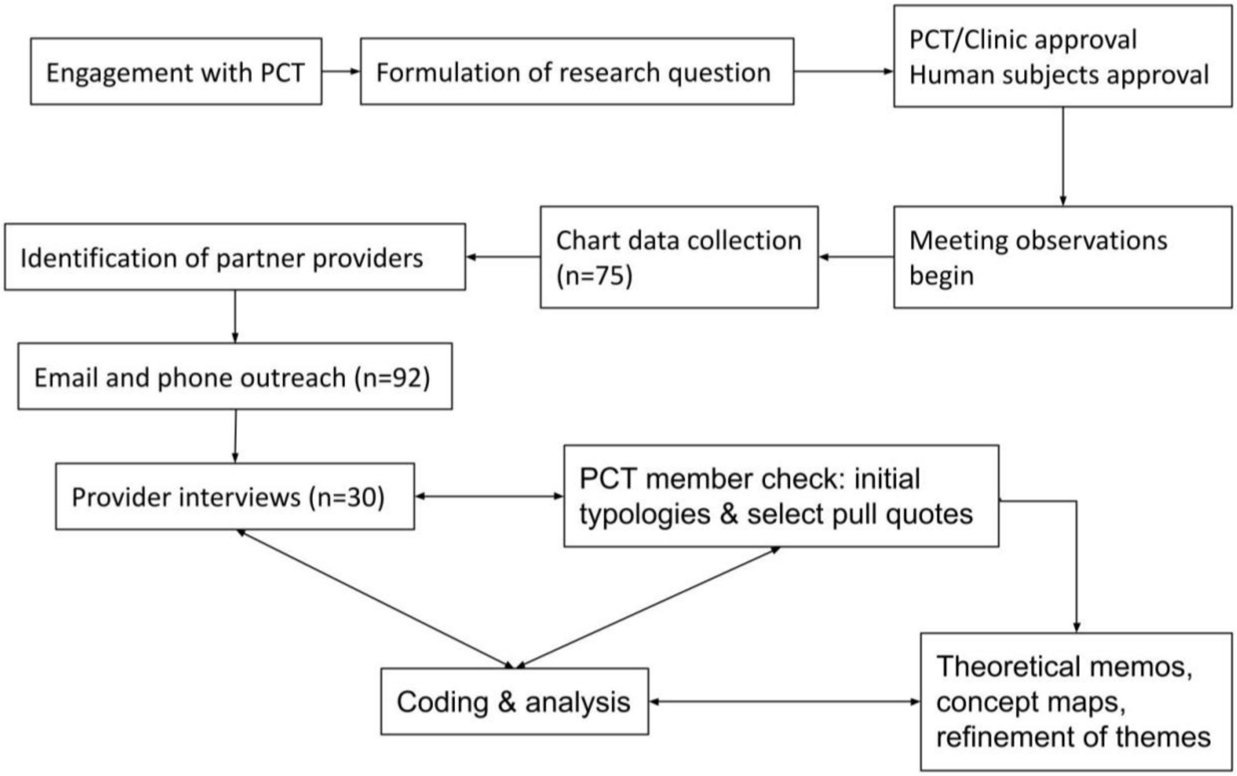
Grounded theory has been used in social science research for nearly eight decades (Glaser & Strauss, 1967). Classic grounded theory approaches, while described by some as epistemologically flexible, are generally oriented to positivist and post-positivist orientations (O'Connor, Carpenter, & Coughlan, 2018). Constructivist grounded theorists, however, acknowledge relativity in their assumptions about "reality" (Charmaz, 2014). These assumptions then require attention to researcher position and study context (Charmaz, 2014). Constructivist approaches to grounded theory reject the expectation that researchers be unfamiliar with the research topic and existing literature prior to data collection (Charmaz, 2014); this allows for constructivist researchers to approach the study with existing research questions with which they must be open and flexible.

This methodological approach was chosen for several reasons. This exploration aimed to explore “what is actually going on” (Glaser, 1998, p. 21) in the places where older adults experiencing homelessness were receiving care. Constructivist approaches align with existing theoretical understandings of human geography. In geography, space and place as topical areas of study are, like constructivist grounded theory, assumed to be dynamic, relational, and able to contain co-existing and contradictory truths or experiences (Allen & Davey, 2018). The study relied on the interweaving of multiple sources of knowledge, and anchored this process in a historically, culturally, and geospatially specific context (Taylor, 2018). Within this paradigm, relativity and subjectivity were embraced, unlike positivist approaches to grounded theory which typically works to identify causality, present objective truths, or identify broadly-applicable solutions (Denzin & Lincon, 2013). The goal in this study was to make meaning from evidenced trajectories of palliative care patients and the on-the-ground experience of providers in their complex web of care.

Bryant & Charmaz (2019) contend “GTM [grounded theory methodology] is based around heuristics and guidelines rather than rules and prescriptions. Moreover, researchers need to be familiar with GTM, in all its major forms, in order to be able to understand how they might adapt it in use or revise it into new forms and variations” (p 17). Grounded theory requires a specificity in approach that can create variation from study to study and relies on clear explication and systematic approaches to generate trustworthiness, credibility, and quality (Charmaz & Thornberg, 2021). Figure 3.1 depicts the steps taken throughout the project described in the rest of this chapter. This figure details how the sequence of operations in the study aided the comparative analyses and interactive nature of constructivist grounded theory approaches (Belgrave & Charmaz, 2014).

Figure 3.1

Study Design



In the spirit of constructivist grounded theory, I have demonstrated transparency with my research partners, interviewees and readers through disclosure and explication of my position to the research topic and connection to the methods used. I gathered a longitudinal data set with multiple types of data, including: (1) written chart documentation from the PCT team and quantitative information from the sampled charts; (2) field notes from observations of six months of team meetings; and (3) interviews of providers outside of the PCT team in a variety of settings the team and their patients move through. My experience as a provider in these settings in a different city granted me an opportunity to make and state inferences within the interviews, and explore openly the possible differences in experience, perspectives, and opinions.

Community-Engaged Research as Refusal

The existence and continued value of academia is predicated on colonial and neoliberal logics of displacement and dispossession (Grande, 2018) and ableism (Dolmage, 2017). While I have made my personal and professional motivations for this project clear, all dissertations are in some way an attempt to be granted recognition by and belonging in The University. Such a goal warrants skepticism in a time when reform-based efforts toward inclusion encourage complicity in the face of injustices (Kelley, 2016).

Refusal continues to be a useful guiding principle for social justice in social work and social work research. The struggle for justice from within the university requires fostering a fugitivity (Kelley, 2016) in places outside the university where intellectual pursuits are disentangled from the mobility and material wealth offered through belonging and identification with academia (Grande, 2018). The commitments of refusing the university as an academic include a commitment to collectivity, to reciprocity, and to mutuality (Grande, 2017).

As evidenced by the stated motivations of this study and my explanation of the naming of the RASCAL-UP study, my axiological stance is one of liberation. Constructivist approaches are well-suited to community-engaged action research because they allow for a shared narrative and the production of a localized and critical "truth" about the studied subject (Duckles et al., 2019). This project has strived to honor a commitment to collectivity through deep collaboration with the PCT team beginning in 2018 in formulating the intent, goals, methods, and outputs of this project. I collected and analyzed data while spatially immersed in community beyond university walls. In the collection and analysis process, I made efforts to acknowledge and refuse the power given by researchers to misrepresent the researched (Redman-MacLaren & Mills, 2017)—I engaged with the PCT in each stage of the research study formation to ensure our goals, procedures, and outcomes were aligned and mutually-beneficial. This agreement also resulted in a member check with all members of the PCT during the data analysis and write up process (Harvey, 2015).

This dissertation establishes basic research necessary to advance translational efforts toward innovative mobile treatment and residential programs informed by those who will use and work in them. The outputs from this dissertation aim to inform direct practice in multiple service sectors, including the housing care continuum, public health organizations, palliative care and hospice programs, and aging and disability services. Reciprocity is about who I am answerable to as a scholar— the findings of this project will be disseminated in a report to all participants and their networks. In the dissemination of this report, I encourage "talking back" in the hopes of extending a critical reciprocal dialogue surrounding these findings.

On mutuality, Grande (2018) states, "one of the many ways that the academy recapitulates colonial logics is through the overvaluing of fast, new, young, and individualist voices and the undervaluing of slow, elder, and collective ones" (p 61). Central to this project's aims was a commitment to honoring the experiences, desires, and needs of elders whose wisdom has been undermined. To uphold this commitment, we must be in good relations with others through our methods (Simpson, 2007). A commitment to mutuality in this project has meant that I took a non-hierarchical and relational approach with research partners and participants.

Self-Reflective Processes

Intersubjectivity generated between interviewee and interviewer can enhance the trustworthiness of narrative inquiry outputs through shared structural, cultural, and historical understanding (Greenhalgh, 2016). I entered this research with direct formal care experience as a nurse's assistant, social worker, and social work manager across homeless response, aging, and outpatient healthcare settings. Such experiences situated me as a peer with the service providers I interviewed. To account for my values, doubts, and experiences in the interpretative analytic process, I engaged in reflexive memoing throughout the data collection process (Charmaz, 1999). Throughout the process of interviewing participants and observing team meetings, I debriefed with the dissertation chair (an expert in oncology and palliative care systems) to assess my intuitive feelings and/or perception of bias (Onwuegbuzie et al., 2010).

Research Context

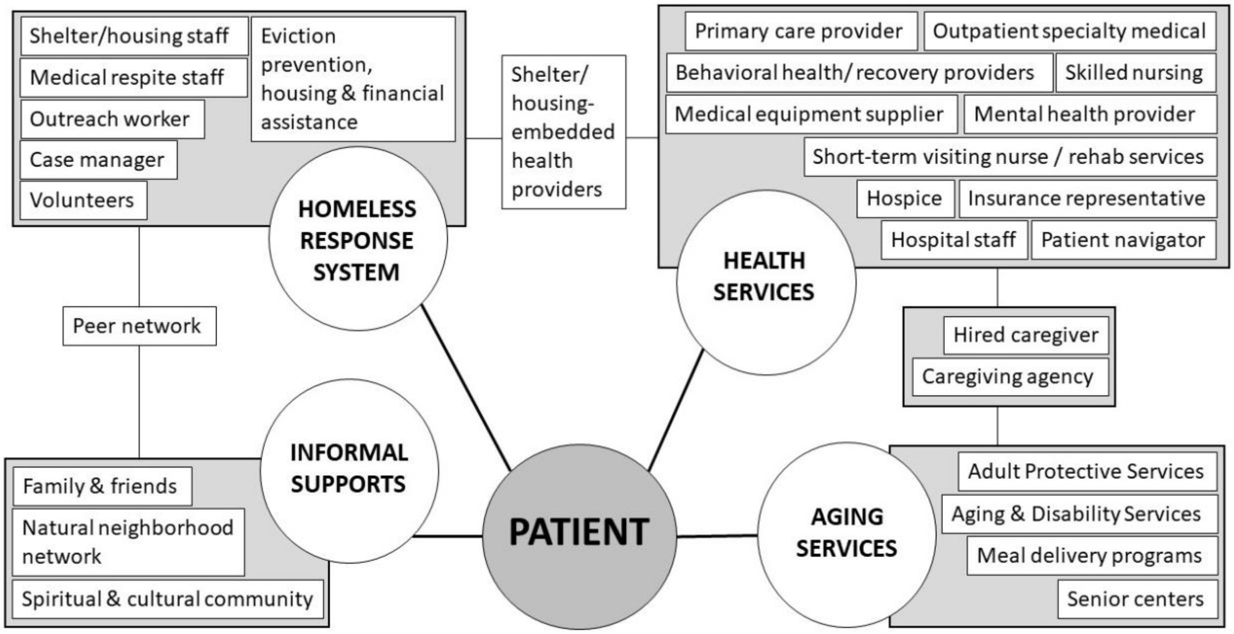
Research Partner

The research study was conducted in partnership with a comprehensive healthcare facility owned by the county and managed under contract by the University of Washington. It is the only Level I trauma center in the Washington, Wyoming, Alaska, Montana, & Idaho (WWAMI) region. The hospital is a 'safety net hospital' that provides priority care to "the non-English speaking poor; the uninsured or underinsured, victims of domestic violence or sexual assault; people incarcerated in the county's jails; people with mental illness or substance abuse problems, particularly those treated involuntarily; people with sexually transmitted diseases; and those who require specialized emergency, trauma or burn care” (Harborview Medical Center website, n.d.). Harborview Medical Center has operated a downtown clinic for over 45 years that has provided medical care, mental health support, and health outreach for people facing intersecting issues of mental illness, poverty, addiction, and housing loss.

Since 2014, the Homeless Palliative Care Program (known in the rest of this document as the “Palliative Care Team” or PCT) has operated out of the downtown clinic to provide low barrier access to nursing and social services for a primarily older population of adults experiencing homelessness who are living with serious, life-limiting illness. The PCT is the only known mobile palliative care team in the United States that specifically serves patients experiencing homelessness. The team consists of one social worker, one nurse practitioner, and one registered nurse. All team members are part-time, working a total number of 80 paid hours per week between them. The team is part of a complex network of care that may include an array of other supports and services, depicted in Figure 3.2.

Figure 3.2

PCT Patients’ Potential Care Networks



Medical eligibility for the PCT program required the presence of a serious or chronic illness, with associated functional changes, increased hospitalization frequency, difficulty with psychosocial issues related to illness, and uncertainty about goals of care, medical prognosis, or symptom management. To be eligible for PCT services, patients had to 1) meet the HRSA criteria for homelessness; and 2) have a diagnosis of any chronic, progressive illness with a medically documented functional decline to qualify for care. This eligibility requirement meant upon referral, patients admitted to the program most recently had overnight residence in: (1) shelters, missions, vehicles, street/outside, abandoned buildings, encampments, or other places not considered safe or fit for occupancy; (2) temporary accommodations such as single-room occupancies (SROs), hotels, motels, accessory dwelling units (ADUs), couch-surfing/doubled up or another informal temporary arrangement, transitional or time-limited housing intended to support a transition to permanent housing; (3) institutions such as prison, jail, residential treatment, medical respite, or hospital without plans for housing; (4) long-term or permanent supportive housing with a history of homelessness; or (5) independent housing with a risk of eviction within 21 days or experiencing homelessness within the past year. Patients meeting the medical eligibility criteria had a diagnosis of a serious and/or chronic illness, and measurable functional changes such as increased hospitalization, difficulty with psychosocial issues related to illness, and/or uncertainty about goals of care, medical prognosis, or symptom management.

The team had an active roster of approximately 45 patients and served between 100-125 patients annually during the four years of this study. Referrals usually came from inpatient and outpatient providers within the safety-net hospital system, but also came from medical respite, supportive housing, shelters, and street outreach teams. The team prioritized referrals based on housing and health acuity to direct limited services to those with higher medical and/or psychosocial needs. Decision-making regarding referral priority occurred weekly in team meetings, and patients waited approximately 3-6 weeks between initial referral and intake assessment. Team intervention ranged from a one-time consult to years of care provision. While death was the most common exit from services by patients on the team, patients also were stabilized through the care coordination of the team and discharged from services upon entrance into supportive housing, skilled nursing care, or reconciliation with informal supports.

The partnership with this PCT offered two unique opportunities of note: (1) to examine patient experiences and outcomes longitudinally across systems of care; and (2) to connect with a network of providers across multiple systems of care who were serving older unhoused people. The PCT team followed unhoused patients throughout their care trajectory. The team saw patients in the hospital, nursing homes and those currently living in shelters, encampments, vehicles, and on the street in the metropolitan area. The PCT had access to a shared medical database that allowed them to view documentation across all local hospital systems except the Veteran's Administration.

Setting

11,751 residents of King County, Washington experienced homelessness on any given night in 2020, with an estimated 30,000 people experiencing homelessness at some point during the year of 2020 (All Home, 2021). Seattle trails only New York City and Los Angeles in municipal homelessness rates across the United States (National Alliance to End Homelessness, 2020). Like many U.S. cities, the local network of public and private emergency shelters is not able to meet demand (Seattle Times, 2017).

In the Seattle metropolitan area, Black, Native Hawaiian & Pacific Islander, and Indigenous people are overrepresented among adults experiencing homelessness (All Home, 2021). The legacy of Seattle's historic strategies for racialized residential segregation, such as redlining and housing covenants, live on in the contemporary rental market (Kennedy et al., 2021). The forced displacement and containment of Indigenous communities in the Puget Sound region is a well-documented part of Seattle history from the mid-1800s until now (Thrush, 2017).

Spatial and geographic factors in the city may shape homelessness and homelessness intervention. Seattle's downtown area has long been a hub for homelessness services (Gibson, 2004) and temporary housing for immigrants (Wong, 2018) and the very-poor (Siegal & Sagarin, 2017). There have been several cycles within the city's history where municipal efforts have been made to center tourism, commerce, and middle-class and luxury housing downtown. The municipal efforts made between in the mid-20th century to improve traffic and create rentals for downtown workers required the destruction of over one thousand homes (Klingle, 2007), a loss contemporarily mirrored in Seattle's loss of nearly 3,000 rental properties between May 2021 and January 2022 (Rental Housing Association of Washington, 2022). Rapid urban development associated with the arrival and expansion of tech companies is likely a factor in the rise in homelessness in the region (Fynn-Bruey, 2019).

Seattle has a main transportation arterial, Highway 99, that boasts a collection of roughly two dozen budget motels, a stretch that became known in the 1970s and 1980s for drug and sex work transactions (Krishnan, 2009). Budget hotels are an important source of refuge—they have been suspected as an early stop in a trajectory for those experiencing first-time homelessness, as well as a temporary refuge for those sleeping outside or using emergency shelter (Lewinson et al., 2014). Seattle has adopted the sanctioning, managing, and organizing of tent, vehicle, and temporary structures through temporary land permits as an interim solution to the strain on emergency housing services (Loftus-Farren, 2011). Due to the temperate climate, the area also boasts a higher rate of unsanctioned encampments than cities with more seasonal weather extremes (Batko, Oneto & Shroyer, 2020).

Municipal and state-level policies dictate responses to homelessness. Compared with much of the rest of the country, Seattle and Washington are relatively progressive in their approach to policing regarding housing, homelessness, and drug use (Beckett, 2016). However, there is still a local movement toward the *transcarceration* of people experiencing homelessness--- the use of carceral systems and logics to involuntarily commit, imprison, or geographically confine people (Rankin, 2021). Local examples include the use of private security in public space within Business Improvement Districts (Glyman & Rankin, 2016), legally-imposed spatial exclusion for those with past criminal offenses from publicly subsidized housing (Beckett & Herbert, 2009), enforced "sweeps" that cause dispossession and displacement for unsheltered people (Winegarden et al., 2021), a web application that allows citizens to report homelessness to authorities (Elwood, 2021), and the neglect of basic human rights like bathroom hygiene (United Nations, 2019). Housing continuum service users still lack the rights of normative citizens, which likely disincentivizes systems from providing the necessary support required for community-based care (Sylvestre, 2017).

While the social, historical, and political specificities of Seattle create a unique environment that may limit generalizability, this setting allowed the opportunity to identify thematic issues increasingly relevant in other areas. This city-specific study can allow for consideration of spatial and place-based distinctions in future localized research.

Sample

Strategy

This exploratory study engaged in a criterion-based purposive sampling strategy. Electronic medical record (EMR) data were retrieved for patients on the active rosters of the HPC team from March 2019, 2020, and 2021. Due to challenges in obtaining consent from patients and their kin, all information was de-identified by PCT practitioners prior to my receipt of data. In the spirit of typical case sampling (Gentles et al., 2015), I selected to review the active rosters of the same month across a three-year period. This allowed for consideration of the role of seasonal variation and COVID-19 in care trajectories in the data collected. In total, I reviewed 75 patient charts.

I attended twelve PCT team meetings between July and November 2021. This sample of meetings were all the formal team meetings. I began in July once the study received IRB approval. In November 2021, the employees on the PCT began having a series of scheduling changes and I was no longer able to attend the new meeting times. Team meetings were between 1-2 hours and consisted of several key events: reviewing incoming referrals; discussing the active roster; confirming current level of care, team planning; coordinating team member schedules, visits, travel, and administrative needs; and discussing any demands beyond patient care (e.g., funder requests).

During chart review and attendance at team meetings, I identified 92 agencies partnering with the PCT in direct service. I used a combination of Internet searching methods and PCT contact lists to contact all these agencies to solicit volunteers for interviews. While conducting interviews, I adjusted my outreach and follow-up strategies to achieve spread across unrepresented types of services. The phone numbers or emails for five agencies were no longer active. One provider declined due to lack of material incentives. One provider declined due to self-perceived lack of direct experience with the population. Three contacts initially agreed to the study but were lost to follow-up or did not receive clearance from supervisors. Fifty-two contacts received at least one email or voicemail but did not follow-up. I interviewed all thirty contacts who expressed interest in participation and confirmed that they had at least some experience working with unhoused people experiencing issues related to aging, serious illness, or end-of-life in their current work setting.

Benefits and drawbacks of sampling strategy

Criterion-based purposive sampling was useful with limited resources for data collection, allowed for an iterative collection and analysis of multiple forms of data, and helped account for potential differences in data both before and during the COVID-19 public health event (Suri, 2011). Limits of this approach were that all statistical procedures were exploratory and should not be generalized beyond this sample. The sample was selected based on my judgment as a researcher, and interpreted by me, which requires additional attention to research bias (Robinson, 2014). COVID-19 and university's emergency restrictions on data collection prevented me from contacting patients directly, which prompted me to triangulate observation, documentation, and provider interview without the inclusion of first-person patient narratives.

Demographics

Chart data. Race and ethnicity in the sample were measured by what was recorded in the electronic medical records. The racial and ethnic composition of the sample reflected the racial and ethnic composition of the homeless population in the greater metropolitan area (Table 3.1), apart from Hawaiian Native and Pacific Islanders. There were no Hawaiian Native or Pacific Islander patients in the study sample, though it is important to note the overrepresentation of these communities in the local homeless population. While the sample captured overrepresentation of Black/African American people in the PCT homeless populations, it may not illustrate the extent of overrepresentation in homeless populations for Hispanic/Latinx and American Indian/Alaska Native people. Absence of multiracial or “two or more races” in the electronic medical records reflect previously established simplifications that medical systems make in the recording of race and ethnicity (Magaña López et al., 2017).

Table 3.1

Racial/ethnic demographics of patients compared to King County estimates

Race/Ethnicity	Sample	King County Homeless Estimate 2020[a]	King County Population Estimate 2020[b]
White, alone (not Hispanic/Latinx)	53.3 %	53.3%	58.1%
Black/ African American, alone	28.0%	25.0%	7.0%
American Indian/Alaska Native, alone	8.0%	15.0%	1.0%
Hispanic/Latinx of any race	9.3%	15%	9.9%
Asian, alone	1.3%	2.0%	19.7%
Native Hawaiian & Pacific Islander	0.0%	4.0%	0.8%
Multi-racial	0.0%	6.0%	5.2%

[a] All Home (2020). Seattle/King County Point in Time Report.
[b] U.S. Census Bureau (2021). Quick Facts: King County, Washington.

9.3% of the sample preferred speaking a language other than English in healthcare settings, the majority of which identified Spanish as a primary language. Small subsets of the population were identified in medical records as lesbian, gay, or bisexual (4.0%), U.S. veterans (6.7%), and undocumented residents (9.4%). The median age of patients was 63 years, and 69.33% of patients were of the Baby Boomer age cohort born between 1946-1964. 86% of patients were over the age of 50. More information about sample demographics can be found in Table 3.2.

Table 3.2

Sampled patient characteristics (n=75)

Demographic Variable	Description
Age	Median= 63 Mean= 60.7
Generational cohort	2.67 % Millennials (1981-1996) 10.67 % Generation X (1965-1980) 69.33 % Baby Boomers (1946-1964) 5.33 % Silent Generation (1928-1945)
Race/ethnicity	53.3% White 28.0% Black/African-American 9.3% Latinx of any race 8.0% American Indian/Alaska Native 1.3% Asian
Gender	77.3% Men 21.3% Women 1.3% Non-binary
Veteran status	93.3% Not Veteran 6.7% Veteran
Preferred language in healthcare setting	90.7% English 8.0% Spanish 1.3% Arabic
Reported sexual orientation	96.0% Unrecorded 4.0% LGB
Reported citizenship	89.3% U.S. citizen 9.4% Undocumented 1.3% Permanent resident

Table 3.3 depicts the primary diagnosis at referral and the comorbidities of patients by body system. Cancer was the most prominent diagnoses to prompt referral to the HPC team (40.0%), followed by congestive heart failure (28.0%), chronic obstructive pulmonary disease (9.3%), chronic liver disease (6.7%), dementia or other cognitive impairment (4.0%), chronic decubitus ulcer (1.3%), and AIDS (1.3%). In addition to referring diagnoses, most patients also had notable comorbid medical

conditions. The mean number of patient comorbidities was 4.85 (SD 1.8) with a median of 5 and a range from 2-9.

Table 3.3.

Sampled patient referring diagnosis and comorbid diagnoses by body system

	Referring Diagnosis	Presence Overall
Cancers	40.0%	49.3%
Chemical dependency	0.0%	69.4%
Endocrine conditions	0.0%	22.6%
Heart conditions	28.0%	54.7%
Gastrointestinal conditions	0.0%	5.3%
Infectious diseases	1.3%	34.7%
Lung conditions	9.3%	46.7%
Liver conditions	6.7%	21.3%
Musculoskeletal conditions	0.0%	65.3%
Neurological conditions	4.0%	44.7%
Psychiatric conditions	0.0%	53.3%
Renal conditions	9.3%	22.6%
Skin and wound care	1.3%	34.7%

Observation. In attendance during team meetings were four key team members on the PCT team during the period of observation: one .5 FTE social worker, one .5 FTE registered nurse, and two .5 FTE nurse practitioners. The social worker, registered nurse, and one of the nurse practitioners have worked on the PCT since its inception. The team experienced a staff change due to nurse practitioner retirement during the study. One meeting (August 25, 2021) was focused on orienting a new staff person. Present at another team meeting (August 11, 2021) were a two-member reporting team from a local newspaper who had been working with the PCT team and two of their patients over the course of several months on a print media feature. While ten of the meetings generally followed similar protocols and patterns, these two meetings were outliers and covered less patient-level details.

Interviews. Interviewees (n=30) were providers in a range of settings, including a variety of outpatient and inpatient healthcare (e.g., primary care, nephrology, oncology, cardiology, palliative care), homeless shelter care, transitional and permanent supportive housing, community-based homeless case management, corrections, and skilled nursing facilities. The interview sample is depicted in further detail in Table 3.4.

Table 3.4

Interview sample characteristics (n=30)

Service type	Role of respondents
Housing & shelter services	• older adult case management supervisor (R8) • supportive housing director (R4, R20, R28) • shelter-based nurse (R30) • supportive housing-based nurse (R14) • public housing eviction prevention (R5)
Hospital	• cardiology social worker (R17) • oncology social worker (R18) • emergency dept social worker (R25) • palliative care doctor (R16, R21) • palliative care nurse (R10) • oncology patient navigator (R9) • nephrology social work director (R15) • neurology social worker (R22) • cardiology nurse (R29)
Community-based services	• aging & disability case manager (R2, R13) • regional director of long-term care and home and community-based services (R23) • hospice social worker (R11, R27) • hospice nurse (R1) • community psychiatric social worker (R19)
Carceral systems	• jail nurse (R26) • forensic street outreach case manager (R12)
Skilled nursing	• VA medical director (R7) • HIV/AIDS social worker (R24)
Medical respite	• case manager (R3)

Protection of Human Subjects

The hospital and clinic administration that hosts the PCT team approved the initial study procedures in early June 2021 (Appendix B). The study procedures were approved by University of Washington's Institutional Review Board (IRB) in mid-July 2021.

Chart Data

Patient data were de-identified in its retrieval from the electronic medical record system. De-identification measures included: (1) deletion of patient IDs; (2) conversion of patients' first name, surname, and nicknames to "patient"; (3) conversion of friends, family members, and pets' first names, surnames, and nicknames to a title specific to their relation to patient (e.g., "nephew", "oldest daughter", "girlfriend"); (4) conversion of health or service provider first names and surnames to a description of their role (e.g., "housing case manager", "floor resident MD"). Spatial identifying information such as specific addresses/locations and names of buildings or agencies remained identified in the first round of data retrieval but were later abstracted during analysis to general whereabouts and relationship to patient (e.g., "Mom's trailer in Wenatchee") or type of location (e.g., "Hotel 1").

Interview & Observation Data

Potential interview participants were contacted via email and/or telephone. PCT members provided experience as to how to best reach providers. Interviews were virtual. Participants were shown a written explanation of study procedures through screen sharing, which was also read aloud by the interviewer (Appendix D). Participants then provided verbal consent to participate in study procedures, to be audio recorded, to have audio recordings sent for transcription prior to de-identification, and to be contacted for follow-up regarding transcript clarity or further interviews. Careful attention was paid to de-identification when sharing excerpts of this data with PCT team members for purposes of confidentiality; evaluative statements made about the PCT team were excluded from member-checking processes as a further confidentiality precaution. When interviewed, I asked participants the level of abstraction they were comfortable with in public-facing reporting and data sharing with PCT team members and recorded this in memos attached to each file; for example, when interviewing specialized programs (e.g., VA skilled nursing, skilled nursing for HIV/AIDS), I received verbal confirmation from participants that no additional abstraction was necessary despite the increased potential for their services to be identified.

During PCT team observation, all team members gave verbal permission for me to attend each meeting and verbally confirmed an understanding that I was willing to exit the meeting at any point in which my presence was felt to be disruptive or in which provider or patient confidentiality needed to be further protected.

Data Security

Field notes, interview audio files and transcripts, memos, and de-identified chart information were electronically stored with multiple password protections. Data was analyzed on a cloud-based analytic software Dedoose (Dedoose, 9.0.46) protected by a unique password only known to me. I used Dedoose on a virtual private network (VPN) sponsored by the university. As the primary investigator, I retained full access to the original de-identified data and was responsible for the integrity and accuracy of analysis.

Measurement

Chart Data

I utilized a standardized retrieval form (Appendix C) to generate quantitative variables relevant to the research question, including patient demographic information, referral information, diagnoses, location chronology between referral and discharge, days of enrollment, number of hospitalizations, length of hospitalization stays, place of death or reason for discharge. I created nominal variables for patient demographic information, referral source, type of referring diagnoses, and location type based on HRSA categories. I generated numerical values for days of enrollment in the PCT program, number of hospitalizations, length of stay in each location, length of time between referral and intake, number of comorbidities, and number of total locations.

Observation & Interview Data

Interview questions explored interviewee's role when interacting with homeless older adults, facilitators and barriers to providing care to unhoused older adults in their setting, typical patient trajectories in and out of their setting, the impact of COVID-19 on services, and recommendations for enhancing unhoused patient or resident care. I also invited interviewees to share other experiences that I did not directly ask about and allowed for conversational exchange for dual construction of knowledge (Mills, Bonner, & Francis, 2006). The full interview guide can be found in Appendix D.

While in team meetings, I followed a field note protocol (Phillippi & Lauderdale, 2017). This protocol suggested writing about the meeting setting, underlying subtext of interactions, verbal content organized by meeting agenda items, and critical reflection immediately post-observation.

Data Collection & Procedures

Chart Data

Collection was guided by following Vassar & Holzmann's (2013) retrospective chart review research design. First, electronic medical record (EMR) data were retrieved from Citrix Epic and de-identified. Word processing documents were generated for each of the 75 charts in the sample. These documents were a chronological compilation of all qualitative information documented by the PCT from patient intake to discharge, and any recorded report of overnight admission to a hospital. In the case of the patient still being actively enrolled in PCT services at the time of collection, data were collected through September 1, 2021. I then utilized the standardized form to extract quantitative data from de-identified charts relevant to the research question. This information was transferred to a spreadsheet format after collection with the standardized form.

Interview Data

Interviews took place in private workplace settings or in private personal spaces outside of work, such as personal cars or homes. Interviews ranged from 33-80 minutes in length and averaged 49.4 minutes. Throughout this time, I kept track of the contact information and any email and phone correspondence with potential interviewees in a spreadsheet to assist with procedures. Interview recordings were professionally transcribed verbatim by GMR Transcription. I listened to the audio recording of each interview while reviewing transcripts for errors and misunderstandings of industry-specific terminology. Transcripts were then uploaded to Dedoose.

Observation Data

Meetings customarily took place in a coffee shop in the downtown area—I would often meet the team at the downtown clinic as it opened so they could gather supplies for the day, and we would walk over to the cafe together. Not only did this location facilitate a pre-existing discretion about sharing patients' identifying information, but also observation of the team members as they interacted with the physical landscape of the service milieu, as the downtown area has a high concentration of health, housing, and social services geared toward those experiencing homelessness. The nurses shared that as a team, they were also “homeless” -- they were not a part of the clinic’s day-to-day functioning and felt cramped and out of place having meetings there (July 20, 2021). In these meetings, I wrote notes on a password-protected tablet, by recording key words during the meeting summaries immediately after. Identifying information, health-related data, and sensitive or illegal topics were obscured in field notes. In my reflections post-observation, I considered non-verbal communication data, including interpersonal space/proximity, pacing of speech and silences, body movements and postures, variations in volume, pitch, and quality, and uses of humor and metaphor to convey abstract ideas (Onwuegbuzie et al., 2010). I converted my handwritten field notes into electronic PDF files, which I uploaded to Dedoose.

Data Analysis

Chart Data

Basic descriptive statistics were generated for sampled patients. I calculated standardized rates (Z-scores) of hospitalizations and residential transitions for each patient so that length of enrollment could be controlled for in examining these data points. Locations were aggregated into categories that reflected the HRSA definitions of homelessness. Patients were coded as unsheltered when they were living outdoors, in a vehicle, or part of a tent encampment. The temporary accommodations category included patients living in emergency shelters, SROs, hotels/motels, transitional housing, accessory-dwelling units, or doubled-up. The supportive housing category included all housing in which residents had a lease and some form of housing assistance (e.g., rental assistance, case management, etc.). Hospitals, skilled nursing facilities, adult family homes, and jail were all retained as their own singular categories.

A conceptual-level indicator typology model was used to classify data (Bailey,1994) with four conceptual pathways identified. Quantitative data from the retrieval forms were entered into SPSS Version 27 (IBM, 2020). Iteratively with analysis of qualitative chart data, I conducted subgroup comparisons of descriptive data; this included hospitalization rate, residential transfer rate, place of intake, and place of death. Preliminary groups were identified through categorizing patients based on patterns in these variables. Initial typologies were refined through a member-checking process with the PCT. Through abstracted through de-identification processes, the PCT assessed the fit of several individual patients into the four typologies using the summative portraits written from reviewing patient documentation. The PCT offered insights into differentiating "housing as palliation" from initial conceptions of housing as an aspect of the legacy activities often facilitated by palliative care providers (Breitbart, 2016). The team also proposed minor linguistic clarifications to different models of housing, considering a cross-sector audience.

A decision tree (Figure 3.3) was created non-algorithmically (Pauwels, 2015) to ensure mutual exclusivity of the four typologies. The root node of this decision tree was if, in the care of the PCT, the patient established a place of care that was acceptable to them. If patients had established this place and did not experience additional transitions that resulted in a lack of return to those places, they were categorized into the Aging & Dying in Place typology. Patients were also placed into the Aging & Dying in Place typology if they had transitions during care but returned to the same location until discharge.

If patients had not established an acceptable place of care, but and had also spent over half of their cumulative time of enrollment in a healthcare institution, they were categorized into the Healthcare Institution as Housing typology. If patients had established a place of care acceptable to them, but experienced death/discharge in a healthcare institution, they were also categorized into the Healthcare Institution as Housing typology.

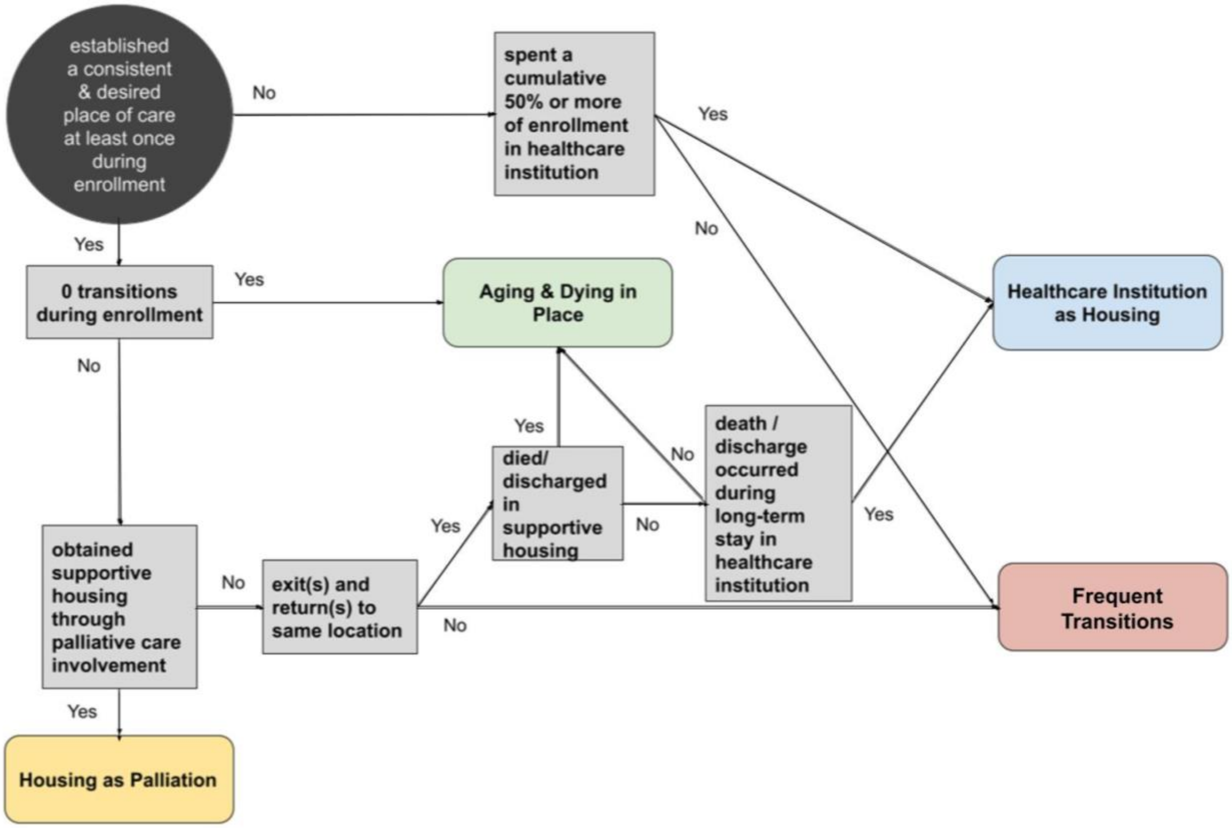
If patients had not established an acceptable place of care and had spent less than 50% of their cumulative time enrolled in PCT services in a healthcare institution, they were sorted into the Frequent Transitions group. The Frequent Transitions typology also consisted of those who established an acceptable place of care at some point during enrollment but had multiple transitions and did not die/get discharged while in supportive housing or during a long-term stay within a health institution.

If patients established an acceptable place of care through involvement of the PCT after experiencing more than one transition of care, they were sorted into the Housing as Palliation typology.

I calculated the Z-scores of several variables to generate standardized rates of days spent in first location, number of hospitalizations, and number of residential transitions. These were the primary variables relevant within the finalized decision tree. I then conducted post-hoc quantitative analyses of the four typologies using one-way analysis of variance (ANOVA) tests to compare means for each standardized variable across the four typologies. I also chi-square tests (Kim, 2017) to determine if there were significant associations between the four typologies and binary variables, such as the presence of specific conditions and demographic factors.

Figure 3.3.

Decision Tree for Four Typologies



Interview & Observation Data

I utilized a review of grounded theory in health research (Sbaraini et al., 2011) as a reference point in shaping analytic procedures. First, I conducted a round of initial open coding with both observation memos and interview transcripts to identify patterns in provider descriptions of facilitators and barriers in each setting implicated in the interviews. Charmaz and Thornberg (2021) suggest engaging with data in multiple ways to enhance trustworthiness. In addition to coding and analyzing the written text in charts, I generated twenty patient portraits throughout the initial coding process. Portraits were narrative summaries of the patient and their journey through care assembled through a synthesis of their chart documentation (Sheard & Marsh, 2019). Portraiture is a constructivist tool that can allow for a comprehensive and summative perspective (Lawrence-Lightfoot, 2005), which provided a supplemental standpoint alongside the initial coding process performed across cases.

A second round of axial coding involved an iterative process of comparing preliminary codes with a priori categories from the retrieval form (Appendix C). In this second stage of the coding process, I also compared how codes differed between individual providers and providers across types of setting. Analysis co-occurred with data collection; selective coding occurred in my constant comparison of transcripts, field notes, and memos. I formulated flexible impressions, wrote memos, and progressively focused my sample and interview questions in this process (Jones & Allony, 2011). For example, I noticed in early interviews that asking about role and responsibilities in the job frequently led to discussion about role confusion or strain to work outside of one’s normal responsibilities when considering service to those who are older, seriously ill, and/or homeless. I began returning to provider role and responsibility after asking about barriers, asking a prompt such as “given your role and responsibilities, how do you interact with those barriers?” to elicit further information about what systems and workers are prepared for and what they’re not.

Next, I compiled provider stories about both facilitators and barriers to care within each setting. Selective coding involved sorting findings by each setting, crystallizing cross-sector perspectives on each setting in this network of care, along with moments where providers clearly articulated opportunities to relieve barriers or articulated a recommendation or wish for the future. I generated an overarching model

(Creswell, 2002) that focuses on the place-specific facilitators and barriers perceived by providers in each setting and how providers sought or hoped to address them.

Conclusion

This overview of the RASCAL-UP study serves to outline the aims, design, procedures, and perspectives used in this project. In Chapter 4, I present findings related to the first research question, "(a) what are provider perceptions of the barriers to working with unhoused older adults across housing and healthcare systems? and (b) what opportunities do healthcare and housing providers see in achieving patient-centered care for unhoused older adults?". In Chapter 5, I present findings for the second research question, "what are the locations of treatment and transitions in housing experienced by unhoused patients receiving palliative care?".

CHAPTER 4

FINDINGS: BARRIERS TO CARE FOR SERIOUSLY ILL UNHOUSED PEOPLE

Due to the social and political production of illness, disability, and early death discussed in prior chapters, those experiencing homelessness are likely to encounter the healthcare system. The challenges in addressing healthcare concerns of patients experiencing homelessness is well-established. Homeless response services such as emergency shelters, temporary and permanent supportive housing, and mobile outreach promote health access (Yu et al., 2017), but are not always designed or structured to support serious chronic illness, functional changes due to aging, and end-of-life care needs (O'Carroll et al., 2017). The palliative care team (PCT) was developed as a bridge to address the needs of unhoused patients facing serious illness whose needs and interests could not be sufficiently attended to in either healthcare or housing systems. By looking across systems implicated in unhoused patients' complex networks of care, the overall needs, barriers, and opportunities for person-centered care were more fully examined.

This chapter identifies barriers to care across systems and outlines the possible changes that can promote better quality care for unhoused people with serious illness. In this chapter, I consider unhoused patients' utilization of eleven settings, which are presented in four categories: (1) permanent housing; (2) temporary accommodations; (3) healthcare institutions; and (4) carceral systems. I interviewed service providers across patients' networks of care to obtain their perceptions of barriers, facilitators and recommendations for future efforts. Table 4.1 depicts an overview of provider-identified barriers, existing facilitators of care and opportunities for patient-centered care across four categories of settings.

Table 4.1

Provider-identified opportunities for enhancing homeless palliative care

Setting Type	*Setting*	*Facilitators*	*Barriers*	*Recommendations*
Permanent Housing	*Supportive Housing*	• Privacy • Individual bathrooms, mini-kitchens • Subsidized rent • Opportunities for community • Case management • Opportunities to move apartment units within agency	• Limited partnerships and communication with aging & healthcare services • Staff shortages & strain • Housing staff's limited training and comfort with end-of-life, serious illness, & aging • Historical increase in acuity of tenant needs with coordinated entry	• Training and education: (1) for housing staff and admin on serious illness & aging; (2) for health partners on SMI, substance abuse, trauma • Full-time on-site healthcare with physical space • Shared caregiving in buildings through coordinated Medicaid LTSS
	Public Senior Housing	• Subsidized rent • Opportunities for community • Neighborhood connections	• Slow repairs and environmental modifications • Insufficient protections from eviction	• On-site case management, senior services • Enhanced eviction prevention efforts, tenant rights
Temporary Accommo-dations	*SROs, Hotels, & Motels*	• Privacy • Storage • Decreased exposure to health risks	• High expense without voucher • Limited on-site staff and security	• Increased staffing • Capacity-building and partnership-building for

			• Less flexibility to make individual modifications	visiting health services
	Tiny Villages	• Privacy • Few restrictions to eligibility and continued residence • Modular and adaptable environment • Collective/ communal structures encourage peer support	• Limited storage • Reliant on volunteer and neighborhood support • Small spaces limit use of durable medical equipment, caregiving	• Toolkit for accessible design • Mobile health & mental health services • Enhanced liaising with and volunteer recruitment in surrounding neighborhood(s)
	Emergency Shelters	• Kinship between shelter users • Staff flexibility and agility in accommodating health challenges • Free of charge • One meal on-site daily • Does not typically require documentation	• Highly inaccessible • Zero-tolerance policies for alcohol and drugs • Congregate settings can promote vulnerability of older or unwell people • Limited hours • Risk of losing spot if unaccounted for	• Extended daytime hours • Toolkit for accessible design • Coordinated entry reform
Health Institutions	*Skilled Nursing*	• Medical supports • On-site meals • Potential for goal-oriented services (PT/OT)	• Admissions restrictions and limitations • Limited knowledge of trauma-informed, harm-reduction approaches	• Lowered barriers to admission for those with co-occurring disorders • Culture Change strategies implemented in Medicaid/

			• Zero-tolerance policies for alcohol and drugs • Restrictive residential policies /limited freedom of movement • Very little personal spending money	Medicare-run programs • Geographically located in familiar, acceptable, accessible places for homeless pops • CCRC operated by supportive housing
	Adult Family Homes	• Specialized personal care • On-site support for end-of-life care • Neighborhood setting	• Low incentives for taking Medicaid/ dual-enrolled patients • Limited support for mental health/ behavioral health needs • Zero-tolerance policies for alcohol and drugs • Limited privacy and choice for residents • Very little personal spending money • Lack of oversight/ regulation	• Increased Medicaid rates • Incentives for training/ certification, admission, and retention of people with co-occurring disorders • CCRC operated by supportive housing
	Hospitals	• Potential for constancy and familiarity • Capacity to support comfort and/or	• Not intended for long-term stay • Not equipped to assist with ongoing psychosocial and	• Training partnerships with housing and shelter providers • Mobile health outreach for unhoused older adults

		longevity through medical and nursing support, pain management	environmental issues - Restrictive in what patients can do while in care - Can engage in punitive approaches with clients	- Interdisciplinary training for inpatient healthcare workers on homelessness
	Medical Respite	- Can assist with health concerns - Knowledgeable of and familiar with homeless populations	- Time-limited - Not intended for palliative care/hospice use - Shared sleeping and bathroom areas - Some residential agreements (e.g., curfew, no on-site drug use) - Risk of losing spot if unaccounted for	- Increased flexibility to length of stay limitations - Residential hospice for people experiencing homelessness - CCRC operated by supportive housing
Carceral Systems	*Drug Treatment*	- Structured, insular, and secure environment - Detox/ withdrawal management aligned with palliative care practices - Covered by insurance - Free meals	- Time-limited - High demand, limited supply - Punitive, abstinence-based approaches to care	- Harm reduction/ Housing First as diversion - Respite-based diversion strategies
	Jail	- Addresses basic needs of food, shelter, basic healthcare	- Health services do not support patient-centered,	- Expanded and improved compassionate release programming

			palliative approaches • Inherently punitive, limited agency • Time-limited • Isolating, limited opportunities for community, meaningful contact with in-house providers or outside supports	• De-privatization of corrections-embedded healthcare programs • Formal peer caregiving programs

Permanent Housing

Supportive Housing

Supportive housing is widely embraced as a housing option, particularly for those with histories of institutionalization, chronic homelessness, mental illness, substance abuse, and others who need ongoing embedded supports. R12, a street outreach case manager working with unhoused people on probation, parole, and reoccurring arrests, shared that receiving a placement in permanent supportive housing “transforms” her older clients with medical needs. She noted how simple changes like sleeping indoors, having access to a kitchenette and a bathroom, and having access to wound care could dramatically stabilize health. However, she added a caveat:

> But then, there comes an in-between time where maybe people are less able to care for their ADLs, and you start seeing people fall, and we’ll move into in-home care and having a caregiver be there as much as possible. I think what gets kind of blurry is that point after that, where maybe permanent supportive housing staff are find themselves having to help people up and out of bed more and do

> things outside of their scope of care. It becomes that question of are they quite at the level of need as a SNF? A lot of pressure gets put on staff to take on some more caregiving type roles. And with people with certain substance use or behavioral health issues, it almost feels like it's not even an option for them to go somewhere else. There seems to be almost a bottleneck. (R12)

Supportive housing staff are trained to support residents in living as independently as possible. In combination with barriers to entry to skilled nursing, residents' gradual declines and opposition to relocation may mean supportive housing programs are retaining residents past when is reasonable or expected without knowing what additional supports for at-home living might exist. Interviewees working for or in supportive housing environments were emphatic about the intention and care that housing staff invested in residents, particularly those who were aging or experiencing serious illness. A respondent in hospice admissions (R27) and a hospice nurse from another hospice agency both expressed that the loving presence and mental health expertise of supportive housing staff enhanced at-home hospice. In the words of the hospice nurse who contrasted supportive housing with independent apartment living, "some managers are freaked out that I would even want to talk to them, particularly in more expensive apartment high-rises. They're like, 'oh, the hospice nurse wants to talk to me? That's not my responsibility.' So, a person, if they're living alone on hospice, even though they have money, they have a lot less support" (R1). The healthcare worker embedded in supportive housing (R14) acknowledged the openness of supportive housing to collaborating with serious illness, aging, and end-of-life care, sharing her observations that when housing staff feel supported from a resident's health team and social connections, they stopped pushing for relocating older adults to institutions like skilled nursing.

A housing program director (R28) shared how working full-time where residents live created an intimate knowing of both residents' health status and healthcare goals; he was clear that such caregiving relationships in this environment also had high emotional stakes, and often resulted in disenfranchised grief and burnout for staff. This burnout was amplified by the change in demographics in supportive housing over the years—this manager explained how after the VI-SPDAT was implemented in the region, "ultra-vulnerable people" (R28) were prioritized for placement in available units. The manager reported that the culture of the buildings shifted toward "residents with less experience living indoors," including people with medical vulnerabilities, histories of violence, and more disruptive patterns of substance abuse. This dynamic increased staff turnover and limited their capacity to provide compassionate support. An aging and disability case manager reinforced this idea in observing that his job with older adults in supportive housing often entails mediating with housing providers and residents when they're "on the very precipice of becoming homeless again" (R2) due to behavioral issues or biohazard risks that have emerged after changes to health and mobility. For example, several providers noted that urinary and fecal incontinence was often a driver of transfers out of their settings, particularly when patients had comorbidities like cognitive impairments or mobility challenges that limited independent clean-up. Multiple interviewees (R4, R13, R20, R28) discussed hoarding behaviors, which was also a topic of frequency during PCT team meetings when discussing patients in permanent and transitional supportive housing. Providers identified compulsive and disorganized collecting as a perpetual eviction risk that was hard to respond to, particularly with a subset of older residents actively using methamphetamine.

Several providers familiar with supportive housing noted educational opportunities for healthcare professionals entering the permanent supportive housing setting. A nurse embedded in a supportive housing building believed training healthcare partners could greatly reduce barriers in supportive housing:

> CNAs [certified nursing assistants] were afraid to be in the building because they were terrified of the residents, and for the most part, people here are not dangerous… I know how to keep myself safe in this environment, and I think that other nurses in the community, home health nurses, can be trained to do the same. (R14)

Respondents such as this on-site RN noted the benefits of training for chore workers and nursing assistants. Some acknowledged the barriers to training, including high turnover (R2, R13, R23, R28) and the need for financial or educational incentives (R2, R6, R22, R23). A housing program manager (R28) and a community health provider (R13) explained that sometimes care workers faced racialized and gendered verbal abuse, particularly from residents who experienced psychosis. Housing staff may be trained in trauma-informed care, de-escalation strategies, and motivational interviewing and harm reduction techniques, but visiting health supports likely were not. A housing manager described how visiting health supports were not always aware of the access needs or protective coping strategies of those with serious mental illness:

> Home care has a two-hour assessment process. That’s a massive barrier. For somebody that you can barely keep in your office for 20 minutes at a shot, and then they have to hangout for two hours? People can’t always look that far in the

> future. Say you've got somebody in a wheelchair who, for reasons of pride, doesn't want to say, "Well, I can't mop my own floor, I can't sweep my own floor." You are coaching, as a case manager in the world with that person. And then when they're with the assessor, and the assessor asks, it's "Oh yeah, I can mop, I can sweep, I can mop." And then the assessor says, "oh okay" even though it's readily apparent-- this person has one arm and no legs there's no way they're mopping the floor. (R28)

The interdisciplinary nature of housing services was another area where providers expressed barriers with healthcare partners who were not accustomed to the variety of services patients received. This included training health professionals on how to communicate more simply to housing staff, to consider the role of housing personnel in the care networks of patients, and to invite them into care planning and discharge efforts. Another housing director (R20) discussed how the history of some supportive housing programs influenced this type of collaboration:

> We've worked with the medical case managers with HIV services, and so between the medical case manager and the housing case manager, we work together to keep that client in their housing. They're for our senior population now— 10 years or 15 years ago, our people were dying. Now, people aren't dying from HIV or AIDS, they're getting old, they're dying from normal old-age things-- a lot of times, things that are exacerbated by their diagnosis. (R20)

While on-site nursing services in supportive housing buildings has become increasingly common, interviewees noted implementation barriers to what was expressed as a necessary addition to the supportive housing model. R14 and R28 discussed how buildings must have private on-site rooms for health and mental health care, and that the expectation that healthcare workers can successfully deliver services in patients' studios is fraught. Providers discussed how apartment conditions, like hoarding or infestation, as well as inherent features of the apartment units, like lighting or layout, may impact their ability or comfort providing care. Supportive housing nurses are split between too many sites, and often contracted through a different agency than the housing agency, which created communication barriers, differential expectations, and delays in rapport building with residents. Further, the "activist nurses" (R28) who worked in community housing, harm reduction, and mobile care were not always perceived as having important contributions in the eyes of inpatient surgeons and doctors when advocating for patients. Nurses were also limited in their ability to prescribe and renew medication.

The "bottleneck" in supportive housing was reflected succinctly by the medical director for aging services at Veteran's Affairs (R11), who also acknowledged a "well-recognized hole in placement options when someone has some functional impairments, but not enough to qualify for skilled nursing." The regional director of aging and disability services also shared ways in which supportive housing has adapted to the systemic push toward home-and-community-based services:

> Our assessment tool is going to generate fewer hours for them [supportive housing residents]. It's not necessarily enough hours to entice these caregivers and their agencies if you only have one client down there and it's gonna [sic] be a four-hour shift. What we're trying to do is work with agencies to say, ok we have five people in the building that need care. One caregiver can go to each of their units and say, hey, I can help for an hour or two today. Just doing that on an as-

> needed basis. Because part of the problem is a lot of these people in supportive housing aren't used to keeping a schedule. (R23)

The PCT team saw movement toward shared caregiving models as wise. In team meetings, they discussed a patient who had been housed and enrolled in a Programs for All-Inclusive Care for the Elderly (PACE) program. They were comfortable discharging the patient from services once he had wraparound care from PACE and felt if all residents in a building could be enrolled in a comprehensive insurance plan with the same program, caregiving and nursing opportunities could expand (August 11, 2021).

Public Housing

Only one interviewee, an eviction prevention case manager, had experience working for low-income public housing. When asked about entry points to public low-income senior housing, he said:

> Senior buildings are primarily for people that are aging in place. So, they literally have been in public housing a long time, but a senior-specific building is a better fit when people are that age. They do have some physical modifications that cater more to mobility issues, they're smaller and have a tighter knit kind of feel to them as far as the community and amongst neighbors. I think there definitely are some other folks that had events happen in their life-- lost a home, went through some financial crisis—and all of a sudden, they're in public housing. That's a different dynamic. There's some of each scenario. (R5)

As stated by this interviewee, older adults may gain entry to public housing through rapid re-housing programs when crises like bankruptcy, medical debt, housing inaccessibility, or excessive rent burden occur. Supportive housing and outreach providers in the sample discussed the utility of end-of-life housing vouchers sponsored by the county housing authority, stating that grave disability will expedite placement for those eligible. The success of these vouchers is dependent on one's informal and formal care networks and the 'fit' between their needs and the environment. Not all aging residents had the support from friends, family, neighbors, and service providers to maintain independent living. When asked where he saw older adults going when they're evicted from public housing, the eviction prevention case manager shared:

> Nursing facilities, most often. Sometimes, unfortunately, to shelters or to the streets. And that's just heartbreaking, that's obviously why we're out there, to prevent that. Honestly, there's not a lot of in-between kinds of housing that's supportive of their needs and not totally independent. Most of those types of housing, like adult family homes, are expensive. People on public assistance, it literally takes all their monthly income just to pay for that. Money well spent in my opinion but getting folks to understand that and the idea that they're gonna [sic] have $40.00 a month to spend on anything else, it's a hard sell to make even if they've got chronic issues. (R5)

Providers across many sectors acknowledged that the cost of care in residential long-term care was a barrier, particularly for those living in independent settings who were used to managing finances at their own discretion. A community hospice nurse had a novel idea for preventing public housing eviction:

> "I do wish that the people who live in Housing Authority buildings had more support, I wish that those were more like supportive housing. I know that that's not realistic, but that's my wish, because Housing Authority patients, those are

> the hardest patients because they just don't have as much, in terms of money or support.” (R1)

While programs like eviction prevention case management may connect residents with resources and offset low-income older adults’ loss of housing, providers noted the potential benefits of more hands-on case management and health supports in facilitating aging in place.

Transitional Housing & Temporary Accommodations

Single Room Occupancies, Hotels, & Motels

There is a long history of single-room occupancies in the downtown area of the city where research was conducted, some of which still function independently and some that are now operated by supportive housing agencies. The buildings are relatively low-touch between staff and residents. Social exchanges and interpersonal dynamics are mostly dependent on resident-to-resident relationships. A community-based hospice social worker (R11) provided anecdotes of the interpersonal vulnerability he witnessed among patients in this setting—notably, on a visit alongside the team nurse, “we were in a patient’s SRO with the door ajar and a hand just came through the door and started digging through the patient’s pocketbook.”

Hotels and motels were frequently cited as locations of care when observing PCT meetings and interviewing providers. A street outreach worker (R12) shared their experience doing case management during COVID, stating,

> “I’m personally seeing on my caseload a lot of people who used to stay more in shelter spaces and are just outside more. I haven’t had any clients specifically benefit from hotel vouchers, just by the nature of how it works. It depends on what encampment you’re in and if the city is like, ‘that’s the one we want to

> target.' If you're going to sweep someone's encampment, placing people in hotel rooms is [the least we can do] -- when I go to encampments to see clients, that's what they're asking most—are we going to get offered a motel voucher?"

The street outreach worker was among other voices reflecting on the general acceptability of motels. Motels were described by interview respondents and by the PCT team as places where privacy, access needs, and continued cohabitation with a romantic partner and/or a pet were facilitated. Having space for storage, heat and air conditioning, a private bathroom, and a mini-fridge and microwave allowed patients to have more agency in their care and promoted better health outcomes.

Medical hotel and motel programs existed before the pandemic with varying degrees of success in providing more stable housing. A housing manager spoke about a now-defunct motel program her non-profit agency once had for those with high medical needs:

> We had too many instances where clients were not getting the care they needed and were decompensating. Yes, they had a roof over their head, but they struggled in that setting without support. We had clients that were incontinent, we had end-of-life clients, cancer, all that stuff. But if we can't have the right staff there at least three days a week for all those clients – and we couldn't-- there's no integrity in calling that program a medical program. Because there were situations that arose-- we had a guy who was in a wheelchair get hit by a car-- and we were just like, no, this doesn't work for us anymore. (R20)

While the COVID-19 pandemic may have drawn attention to the potential use of hotels and motels as an alternative to crowded emergency shelters and as a venue for health-affirming, de-congregated care for people experiencing homelessness, providers warned that proper funding and staffing would be necessary for successful implementation.

Tiny Home Villages

Two of the interview respondents were directors within non-profit supportive housing agencies and had Tiny Home Villages within their management portfolios. When describing the unique opportunities that the village mode offered to those over age 50, who made up “at least a third to one half” of the total villagers, one of the housing directors shared,

> Especially when it skews towards an older demographic, it’s autonomy…a lot of folks that are a little older are not used to this new world where no one has anything, you know where we have [micro studios] and you borrow cars with a group of people. They’re used to that independence and so the tiny house kind of facilitates that. It has limits to it, but I think not infantilizing people – not like they have to come ask ‘Mother, may I’ to unlock a door for you or to access some resource like shower or kitchen – that autonomy allows people to retain some of their dignity and especially when someone is sick or maybe they have mobility issues, their dignity is already being taxed. (R4)

One unique benefit of the Tiny Home Village model is their modularity. Providers spoke to how being able to easily relocate the tiny homes as necessary was helpful in negotiating their relationship to the neighborhood at large; their portability increased the public perception that their acceptance of the Tiny Homes could be revoked, which allowed for the model to clear initial barriers to implementation. Structures could be adapted seasonally through the distribution of space heaters or air conditioning and fans. The adaptability of the tiny home structures also allowed for accommodations related to aging, disability, and health:

> In our village, if somebody has a mobility issue, we have a row of houses that has a ramp that goes to the houses. One side of the hygiene trailer has a ramp so that they can get to the bathrooms, the laundry, the showers. If we didn't have one of those disability units available, we have portable ramps that we can provide. (R4)

Tiny homes can be modified to accommodate respiratory needs better than congregate shelters by creating safe storage for oxygen tanks or providing electricity. Sometimes, accessibility isn't fully understood until during implementation. Providers spoke to the flexibility of the Tiny Home setup:

> When we were leveling the ground with gravel, they used a gravel that was too large. And so, then you see someone on a walker or a wheelchair struggling to get through it and so every new village has been an iteration and lessons learned for design. So, we've seen the scenarios play out again and again, we've solved a lot of the problems, right? You look and – to the shower trailer, to the kitchen, and then to pathways that lead through the village that do not have gravel – we have ramps, slopes, and it's like decking. It all snakes around the structures so that you're elevated the whole time. You can literally access every part of the village without ever touching the gravel. (R20)

One director (R20) discussed the three times in the past three years that she used grave disability vouchers to move people from the temporary Tiny Home setting to a more traditional apartment setting where hospice could be delivered, since in most cases, durable medical equipment like hospital beds and caregiver accommodation is not feasible with the square footage available in Tiny Homes. The other spoke of a particular Village with a high median age and a lot of medical need that had “four or five” consecutive deaths within a year (R4). Housing directors also shared the experience of the Villages living up to their name—having a mini-neighborhood allowed for informal networks of care to blossom, created an inclusive space around racial, ethnic, gender and age differences, and insulated villagers from the indignities of being on display as homeless in and around the neighborhood. One of the consequences of informal care and kinship, both directors noted, was that grief could be shared in the Tiny Home Villages. Tiny Homes facilitated important social-emotional processes needed around end-of-life and death:

> A villager could die at the village, or maybe they’re hospitalized and never return--it happens multiple ways. One thing I've seen the Village do is, family members often want to come and take some belongings or mementos, to talk about that person and their life. You’ve come to know them, you were basically living in a house with many rooms, with what the village is like. So, they’re your neighbor and they [loved ones] can meet people that spent time with them and draw emotional support from that. (R4)

The directors of the Tiny Villages were not the only providers to note their potential strengths. The PCT team strongly endorsed the use of Villages, sharing that most of their older patients felt safer with their own space than in the congregate shelters, valued the privacy tiny homes allowed, and didn’t have to deal with agitating sensory experiences (“hearing or smelling other guys”). Unlike many shelters who closed during the daytime hours, the PCT noted how older people with chronic conditions valued the ability to stay in one place throughout the day (July 14, 2021).

Providers noted how mobile health could enhance the current iteration of the Village model. They continued to identify the need—noting that the population that a low-barrier model like the Villages attracted are a population of older people with the trimorbidity of medical conditions, active substance use, and mental illness (R4, R20). One housing manager (R20) shared her staff had a learning curve and had to develop a resource bank around aging programming, advance care planning, and health management. She also discussed the fallibility of coordinated entry assessments, where older and seriously ill tiny home residents are not always scoring high enough to be prioritized for permanent supportive housing. Given the current pressure on the Village model to adapt and respond to aging issues, providers emphasized the need for emplaced or regular visiting nursing, psychiatry, and peer support/recovery services. An inpatient cardiology nurse, in discussing her partnership with the PCT program, shared,

> Them going out to their shack, telling me exactly what it looks like, where they are, what it's really like outside of what we see at the hospital. It's the whole thing with being able to follow them into these places and prescribe for them so that they don't have to come in. It makes a big difference. (R17)

Providers emphasized the power of home-visiting health services: "Regular visiting services bring people inside our neighborhood, their [residents'] homes…it is a reestablishment of community bonds that have disintegrated." (R4) Specialized mobile treatment on-site at the Villages could reinforce the networks of informal support between villagers and reduce the insularity of the Villages. Respondents noted that involvement from volunteers and professionals from surrounding neighborhoods could help medical emergencies, increase continuity of care, and facilitate stronger integration into the local community.

Emergency Shelters

Among the many shelters the PCT team worked closely with, they spoke at length about a shelter specifically for men over 50 years of age. The RN on the PCT team shared that many of the men who lived there had a history of work that involved short-term contracts and travel, such as truck driving, construction, or fishing. As they got older, acquired an injury or disability on the job, or got into drugs, they could no longer work or afford to move (July 14, 2021). The director of this shelter (R8), who also oversaw senior services at the shelter's parent agency, provided a detailed picture of the environment there. She voiced her perspective that shelter services were designed to support two kinds of exits from homelessness: family reunification and employment. She emphasized that neither were realistic options for the men in this 225-bed shelter:

> There just aren't that many who are going to resolve their homelessness through good steady work that's going to keep them comfortably housed…people have to stay a longer time to get housed. What we're seeing lately are people who need subsidies and a degree of support" (R8).

Emergency shelters were noted by shelter providers and outreach workers as highly inaccessible on several fronts. Physical accessibility was limited—in various meetings, the PCT team identified patient challenges like sleeping on mats on the floor or in bunk beds, not having adequate medication storage, challenges with successful medical transportation pick-up and drop-off, and mobility challenges, particularly navigating older buildings or church-based overnight shelters that may be grandfathered into compliance with Americans with Disabilities Act (ADA) standards. The PCT nurse and the shelter director (R8) noted that the shelter for older adults was across a set of train tracks and far from public transportation—while those familiar with the shelter could pick up a shuttle at the program's day service center located in a more central area, walk-ins were limited by the physical location. The PCT nurse had an explanation for this:

> Downtown is supposed to be a tourist center for the cruise lines, not an open-air homeless market. So, whenever there's an excuse to close services up for the day or relocate services further away, it happens (July 20, 2021).

The PCT team also noted more nuanced accessibility issues, ranging from gender-segregated shelter space, fears of safety around younger shelter users, shelter meals that aren't kosher or halal, and theft of patients' medications and mobility aids. Particularly in religiously-affiliated shelters, they may be zero-tolerance policies on substance abuse, where "people can get kicked out in the middle of the night, at 3 a.m. into the elements, for using." (R26)

The bottlenecking noted in supportive housing in the wake of the VI-SPDAT was also observed in the emergency shelters; according to providers, the assessment and prioritization tool does not adequately capture the social and health vulnerabilities facing older people (R8, R28). Providers noted that after a period in the shelter, people stabilized in their health, and are then scored lower in vulnerability than people living outdoors. A nurse practitioner working in a 40-bed women's shelter described what that looked like for the setting as a whole:

> I would say there's probably 15 older women, one as old as 90, who have nowhere else to go. All of them have some sort of mental health component to their care needs, paranoia and memory loss...The shelter tolerates them being there and they try to help as much as they can because they know there's no place else for them to go. Even when the hospital discharges someone who can't transfer out of

> a wheelchair, we'll try to make it work because they know there's no place for that person to go. (R30)

This nurse explained that certain behaviors often marked the last straw before the shelter staff began pushing hard for referral to long-term care or calling EMS with every health event. Frequent urinary incontinence without the willingness or ability to wear protective undergarments was one example of a troubling behavior. Falls, particularly those related to active alcohol or drug use, were another. The nurse expressed fear about resident safety due to staffing shortages and the level of care needed by shelter users. She coped with these anxieties by paying attention to kinship between women in the shelter:

> Some of the women are preying on the elderly women who have cognitive impairments…but then I would say there are two or three women who will look out for that kind of behavior and report it or try to intervene. They have the den for divas, which is a cubicle where the older women are, no bunk beds. (R30)

When providers described the shelters, they often described spaces that were co-constructed by the shelter and its residents to be more accommodating to the specific needs of the older people who stayed there. A PCT team member shared how in one of the men's shelters, patients with pneumonia or COPD can sleep sitting upright against a far wall, and in the same area, there are a limited number of cots for people who can't sleep safely on the floor. Having designated spaces seemed to facilitate kinship, in that it was a visual reminder that people might need help from fellow residents, and that the older residents could keep an eye out for each other.

When asking shelter providers about their wishes for enhancing care for older adults, they prefaced their answers by sharing their hopes were "simple" (R8) or "stupid"

(R30). The suggestions showed how ill-prepared shelters really were to address a variety of health and access needs:

> I want to see a bed. I'm not talking about a cot, I'm not talking about a mattress on the floor, or stacking five mattresses on top of each other so someone can get up. I'm talking about a solid bed. If you were having mobility issues, you need the stability of a solid bed so that you can get up safely. Maybe you can even put on those side rails, or a bedside commode. (R30)

Providers shared that while shelter and supportive housing services were prepared for the needs of homeless populations who were younger and in better health, the entire spectrum of housing care is "no good at dealing with medical needs" (R8).

Healthcare Institutions

Skilled nursing

Two providers who were interviewed worked in skilled nursing at the time of interview. Both programs were specialized: one was the medical director of a Veteran's Affairs skilled nursing program, and the other was a social worker in a rehabilitation and skilled nursing center that historically specialized in HIV/AIDS. Both settings received alternate funding than traditional skilled nursing programs and were created to respond to specific population needs. The medical director at the Veteran's Affairs SNF shared barriers to admission that transcend veteran status:

> Behavioral problems are a barrier. There's this kind of dance that happens to figure out how do we get things tuned up on the ward to the point where the screening process will be successful, and the patient can be taken in. Once they're in, it can be hard to change your mind and decide this person isn't a good fit here.

> Then well, if they're not a good fit here, where are they going to go? There's nowhere for them. If they show a pattern of leaving despite medical advice, then that's also a potential barrier. If we take you, are you going to stay? (R7)

Other providers noted similar barriers regarding mental health and substance abuse when trying to refer to SNFs. A home hospice social worker commented on how rare it is to find long-term care settings that accommodate such behaviors:

> It’s hard to place homeless people in skilled nursing and adult family homes. Smoking is a big barrier; these places won’t touch a smoker with a ten-foot pole unless they’re completely bedbound. Historical or active drug use, criminal records, behavioral issues, and mental health issues, all of that are things SNFs don’t really handle well and won’t take on (R11).

The hospice social worker illuminated the role of liability in determining admissions. Several providers noted how patients with prescribed oxygen were seen as a fire hazard and would be denied admission without the promise of tobacco abstinence. Another commonality between respondents was the acknowledgement that recorded histories of behavioral health problems were often a presumed risk to the comfort and safety of other residents. Respondent 12 commented that skilled nursing and adult family homes were not willing to take on the complex behavioral needs of people with traumatic brain injury, a common injury among people with histories of homelessness. The social worker in a skilled nursing and rehab center designed for those with HIV/AIDS shared similar barriers in discharging. She noted that because of the psychosocial toll of chronic homelessness, “the older the patient, the harder it is” (R24) to stabilize them in an apartment with supports in place. She discussed how re-educating older clients with longer histories of homelessness on tasks like how to keep an apartment or how to manage bill payments sometimes threatened their success when exiting short-term rehabilitation to supportive housing. This pattern, she noted, was a contributing factor that created a cycle back into the facility for long-term stay:

> Most people are discharged from the hospital, and they come in to our SNF for rehab for a short time. They leave, find a home, go back to the hospital. [A current patient] was coming back in for rehab but it's changing now, and it looks like she's going to be long-term through end-of-life. The challenge really becomes, how do we tell her that? She completely denies it, like "I will get well, and I will go back to my home." She's been known to us, we see she's declining, we're hearing it's end of life, and you can't tell her because she has underlying mental health conditions, she immediately she gets very upset, very anxious. You're telling her she's not going back to the home she found after all these years of being homeless. This is a 70-year-old you're trying to tell that. It becomes quite a challenge, we understand with her trauma, her history, you feel you can't just tell her she's not going home, that home is done. (R24)

The PCT team tackled this issue directly during their team meetings. They noted that the geographies of skilled nursing were most frequently on the outskirts of the city or in the suburbs, far away from patients' usual health providers and kin relationships. The team struggled with maintaining their own geographic boundaries, stating that many skilled nursing programs were outside their catchment area, but that "if we don't visit, they'll stay forever," expressing that "warehousing is easier than coordinating the complex discharge our patients want." (July 14, 2021). The regional director of aging and disability services (R23) gave some context for this conflict between most patients lingering in skilled nursing or facing precarious discharge. She reported that state mental health hospitals and skilled nursing facilities were being pushed toward a triage model. If a patient has an opportunity for independent living with community-based supports, there is incentive to set up that care. The director reported on a massive closure of "probably more than ten" skilled nursing facilities in the past year due to costs of operation and insufficient reimbursement rates, particularly for people dual-enrolled in Medicaid and Medicare. She added, "they don't like our rates. I don't have hard and fast evidence, but it's much harder to make placements in this county because of the cost of living." (R23)

To address the inaccessibility of skilled nursing for people with histories of substance abuse, mental illness, and/or histories of housing loss, an emergency department social worker (R25) shared her vision of low-barrier long-term care built with older people with homelessness histories and co-occurring mental health and substance abuse disorders in mind. After sharing this vision, she added "I don't think it makes sense for it to be a skilled nursing facility. I think it needs to be an agency that already works well with folks who are unhoused, and who already supports that community. Because, for a lack of a better term, I think it should be trauma-informed. It should be all these different things that I don't really see at skilled nursing facilities, but I feel like I do see more at shelters."

The skilled nursing social worker (R24) discussed how, due to her workplace's specialization in HIV/AIDS, their SNF was more low-barrier than typical SNFs, both in admissions criteria and in day-to-day rules. The SNF allowed for patients to sign out during the day. With the freedom of movement, ambulatory patients who had cognitive wayfinding abilities could smoke cigarettes outside, eat foods of their choice, meet friends, and purchase alcohol and drugs. In this setting, the skilled nursing social worker saw her role as centered around comfort. She noted that other members of interdisciplinary long-term care teams might dwell on medication adherence or patient resistance to a care plan, but her task was to orient the team to a more person-centered approach. She noted the importance of helping patients decorate their rooms, and reported that, "for the ones whom we couldn't get hold of any family, the staff, you know, all of us, we made them feel loved because this was their home." (R24)

Unhoused older adults' intake and admission to skilled nursing was identified as a barrier for both financial and psychosocial reasons. Once in skilled nursing, staff knowledge and comfort, as well as program design and implementation, caused a mismatch in environmental fit for unhoused older people. Providers envisioned low-barrier long-term care options that were operated from a harm-reduction, trauma-informed perspective.

Adult Family Homes

Adult family homes were discussed in twenty-five of the thirty interviews. Whenever they were brought up, providers discussed the immense challenges in referring to adult family homes. For some health and housing providers, adult family homes could be an appropriate site to transfer residential care to, but only if medical needs eclipsed any behavioral concerns in the patients' chart (R8, R24). A hospice social worker (R11) discussed how the low Medicaid reimbursement rates and limited capacity for supporting behavioral health needs drastically limited adult family homes as a realistic option; further, he stated that the referral process was 'bureaucratic and clunky' (R11), so even if an AFH was identified as a good fit for end-of-life care, it often didn't come together before the patient died in hospital. A supportive housing manager (R28) recounted a story in which a former resident he worked closely with for four years was discharged to an AFH and “because of use issues, behavioral issues, ended up back on the sidewalk. Now he’s the guy I give my change to because he’s fallen that far down. And he doesn’t remember me.” An aging and disability case manager echoed his sentiment, sharing:

> Unhoused clients are not good candidates for moving to an adult family home because they are never going to get the level of support they got from their mental health housing provider. The closest we get is a client moving into an adult family home that has a mental health specialty with a mental health provider that comes to visit, but they come to visit once a week at most. My experience with that has been dismal-- in the five years working on supportive housing, I've had three successful moves to an adult family home. (R13)

For patients with private insurance, adult family homes can be a suitable option for hospice care, but the possibility of this for people who are on Medicaid is slim. An inpatient palliative care social worker half-jokingly shared that in her office, they cope with the bleak nature of the referral options through buying lottery tickets:

> We've all decided that if one of us wins, we're going to build a giant hospice residence for people because there's a spot where they kind of fall through the cracks. There's a gap in the care because they may need hospice, and they need the support of hospice as their disease progresses. But where are they gonna [sic] be? Where do you get that care? It’s a pipe dream but we don’t care. What options do we have really unless we can find them an adult family home that will take a homeless patient on hospice? The odds are not very good. You run into that problem again where some places don't take Medicaid, or they only have one Medicaid bed and 50,000 people that need it. (R6)

The financial and behavioral eligibility barriers, a demand that exceeds supply, an arduous and slow-moving referral process, and a lack of adequate supports for coping with trauma, substance abuse, and mental health made adult family homes an unlikely destination for older adults experiencing homelessness. Providers imagined a future in which unhoused older adults could experience later-life and end-of-life care in a home-like residence that was specialized for the population.

Hospitals

Housing and healthcare providers illustrated the complex relationship older people experiencing homelessness have with the hospital. A housing provider (R4) reflected on the carcerality of the medical system, and how the institution itself can be retraumatizing for residents:

> "The cops are scary when they're in the military equipment and you don't know who they are. I feel the same way about medical establishments-- when I'm in the hospital and there's bright lights and people are wearing surgical masks and I don't know who they are, that is a frightening experience."

The nurses on the PCT team noted that inpatient and outpatient medical providers who aren't taking trauma-informed approaches try to "incentivize care through punishment" (August 11, 2021). They illustrated punitive medical approaches with a story about a doctor, who at the time, was refusing to give a patient a soft boot instead of a cast. The patient was unwilling to leave a tent for a shelter, and the boot would allow for better mobility and safety, but the doctor felt offering it would be "enabling" the client. While the medical doctors interviewed in this sample clearly positioned themselves away from punitive approaches, they did identify how, due to social determinants of health, their roles were not always aligned with the needs of patients:

> A gentleman with pancreatic cancer, he was sleeping on the floor of his cousin's RV, and he's like, 'I'd really like a mattress.' Okay, that makes sense, but we're not going to prescribe a mattress. That's just not a thing. He didn't want to live in his cousin's RV, but he didn't want to go to a facility. In that example, essentially, what I'm pointing to is—not to be glib, but the barriers people come in with are the barriers they leave with. He didn't have the resources for a home or a mattress. We're asking him what he wants to do in the final weeks of his life-- he couldn't get there. He needed a mattress. (R21)

An inpatient cardiology nurse (R17) gave examples of how patients' relationships transcended rigid formulations of desired place of care-- either wanting to be in the hospital or wanting to be at home. She shared,

> This guy who just passed, he wanted to be independent. We would get him tuned up a bit, get him so he could breathe. He'd walk off and go home. We offered services, placement, everything, and he was like, 'Nope, I'm going to go live my life.' That was fine because that made him happy, and he would always come back when it was bad.

While perhaps to the dismay of housing providers who expressed frustration with hasty discharges (R8, R28) and hospital administration alike (R17), mobile and alert patients can at least have the power to self-discharge. A shelter director (R8) described this as an "uncomfortable dance" between three parties that, while colored by understanding and sympathy, falls on the hospital: "Both institutions are struggling because there's no solution, but we're serving people we can't serve. Hospitals sometimes have better tools for care and for getting people into more appropriate placement than shelter case management can."

Many hospital providers noted that they developed close relationships with patients with chronic diseases, particularly if they were homeless or facing complex psychosocial barriers to illness management. Inpatient providers in the sample discussed how they were a second home for patients who may not have access to more robust care options. One nurse (R17) teared up talking about a patient for whom she used to dye their hair. An outpatient neuro-oncology social worker (R22) told a story about how inpatient and outpatient social workers assumed the role of housing case management over the course of three years for a man living on a boat with a brain tumor. Another nurse explained how she perceived her role in the long-term care of a hospital patient:

> We've known him [patient] for six years; he wore my husband's shoes…he had a stroke, and one day he was doing a walk around with OT/PT to see if he could manage crossing the streets and he just ran away in his gown and ran back to his apartment because he didn't want to be here. But he couldn't physically take care of himself; we were just watching somebody dying. The suffering was huge and there was no resolution-- no family, and he wasn't going into a nursing facility. So, we just provided some human care, that he didn't die alone…He just needed pain medicine and clean sheets. He could have died in his bed in his little apartment, covered in shit and pee, gasping for air for 12 hours like a fish, dying all alone. That's probably how it was going to end. It's horrible but that's how a lot of our patients die. (R29)

A social worker in dialysis (R15) also told a story of a patient who, while relating to the hospital as a “traumatizing place,” also did not want to die alone at her supportive housing unit and was able to articulate an expectation throughout treatment that she knew those were likely going to be her two options. Providers identified some unique offerings that older and/or seriously ill patients could access at dialysis, including a sense of security (R15), appropriate pain management (R29), spiritual care (R15, R25), physical and occupational therapy (R29), and opportunities for family reunification and reconciliation (R6, R9). In combination with continuity of care providers, the offerings at the hospital made it a satisfactory place for some to have long-term stays.

Education and training were suggested as an opportunity to enhance care for older adults experiencing homelessness. A palliative care social worker had recently transferred to a new branch of her hospital and noted that unhoused populations were much more prevalent in the new place. She commented on the differences in interdisciplinary perspectives while serving a different patient population:

> Patients who are experiencing housing insecurity or are homeless – it’s not something that I think is my strength. I want to come to it from a place of humility. I’m not an expert in that area. I have seen that our providers, although they’re lovely people and have so much empathy, don’t always recognize the role that substance abuse can play. I don’t either, probably, to the extent that I should, but I know that it’s a factor. So, I try to kind of make sure that we’re having empathy. I say to them, I’m pretty sure that when she was 12 years old, she wasn’t saying, “Hey, in 40 years I want to be dying in the hospital of kidney disease and not have any support.” I guarantee that they didn’t grow up wanting this. This is how their life has turned out, unfortunately, and how can we maintain empathy and offer compassionate care? (R18)

The social work manager in nephrology and dialysis (R15) expressed a frustration in having to educate across disciplines around trauma-informed care. She emphasized the need for medical staff to receive training identifying patient strengths and motivations and considering the role of trauma in both experiences of health and illness and medical treatment. An emergency department social worker added that in addition to education and training, hospitals could be doing more in the community. She recommended that hospitals invest in health outreach that specialized in older adults and end-of-life:

> Our hospital is already one of the largest hospice providers in the county, I think having outreach teams would make sense for them. There are so many barriers to enrollment for folks who are unhoused-- I've thought for a while about providing education to housing agencies and shelters about aging, hospice, and palliative care basics so they understand more how to help folks get connected with services. (R25)

The providers interviewed identified a need for more understanding across housing and hospital settings about each other's capacities and roles. Interviewees also commented on their motivation to better serve unhoused people in their settings, and the efforts social workers and nurses alike had to take to educate their peers.

Medical Respite

The city and surrounding areas where this research study took place hosted four medical respite programs of the 134 known programs across the United States aimed at providing recuperative care for the homeless (National Institute for Medical Respite Care, 2022). The PCT team and the providers were mostly familiar with the one program within city limits connected with the safety-net hospital. The case manager interviewed from this respite program (R3) explained that the model was built to provide a safe shelter for brief and acute post-hospitalization care, such as wound care or recovery from surgery. As the average age of people experiencing homelessness has increased over recent years, medical respite has been increasingly used to address gaps in care for people with chronic illnesses:

> Let’s say somebody comes to respite for a wound. When that wound's healed and that's what they're there for, they're ready to go, right? They don't need to stay any longer. They're healed. Maybe, they have some psychosocial stuff that needs addressing, and sometimes, those people would come to me, and I would help make sure that they got connected with long-term services. But with older people or people with palliative needs, they're going to constantly need to go the hospital, even after discharge from respite. Even while they're at respite, they have lots of hospitalizations. The job now is just looking at what those long-term medical providers need to get done, what is most important to address before they leave respite and aren’t in a structured environment. (R3)

Length of stay was identified as a barrier. The respite case manager noted that in such a saturated service sector, other providers relied on their relationship to respite staff and administration for “loopholes” and “backdoor referrals.” The PCT team reviewed a case in a meeting in which a patient at the respite program didn’t have another place to go at the end of the allotted three-month maximum and would face immense barriers if discharged back to a shelter or to the street. She readmitted herself to the hospital and was re-referred to respite immediately after she was discharged and secured her bed for the duration of her chemotherapy (September 14, 2021).

Medical respite was not always an appropriate referral for those who fit the medical needs. Some providers noted that their patients had been discharged from respite for being missing-in-action overnight, for using drugs on-site, or for being a risk for violence. The respite program had shared rooms and a communal bathroom and required patients to not disrupt the well-being of others in the setting. There were also accessibility barriers:

> [Patients] are supposed to be fully independent in managing their ADLs, but we have people who are struggling. We're going out of our way and over what we're supposed to be doing to make sure that they're taken care of, but I think there are situations where it's like, look, we really can't help this person with these things. We document it to paint a picture, so we can have that background information to advocate that they go either to a SNF or to hospice or to inpatient. But sometimes respite really goes above and beyond in attending to their ADLs, which becomes a kind of gray area…I would sometimes help people change, but if somebody's consistently soiling with stools, not accepting Depends and being resistant around tools that would help them manage, then, yeah, that's kind of where it can get convoluted. (R3)

The medical respite case manager also emphasized a gap in care for older adults experiencing homelessness who may need chronic illness management or assistance with activities of daily living, but who may not be appropriate for higher levels of care. The boundaries that systems of care like medical respite are being stretched by current demands, which leaves providers and programs to make care decisions in un-uniform ways.

Carceral Systems

Drug Treatment

While attempts to recruit providers from drug treatment for this study proved unsuccessful, interviewees spoke about two types of drug treatment that could offer a place to sleep: detox programs and residential drug treatment. The nurse working in the county jail had recently transitioned out of a role in county detox and reflected on her role:

> Practically everyone at county detox has been incarcerated in one way or another, some of them in prison for years, and then a lot of people with withdrawal management needs, all of which is palliative, in my eyes. Palliative and patient-centered care is a huge need, I think, especially for people in detox because that tends to be traditionally a punitive place--completely unnecessarily and misguidedly. (R26)

When asked about residential drug treatment, a social worker providing outpatient mental health at a downtown clinic listed several barriers she faced in making referrals. In addition to insurance coverage limitations and bed availability, she shared that the nature of residential treatments varied, and patients familiar with the systems of care had strong preferences. She illustrated this with an example of a recent client who, after working through his ambivalence to recovery said to her:

> He used to come and ask, ‘did you find the place?’ because he only wanted one particular place. And there wasn’t ever bed availability. I think at one point he was very frustrated, he left and disappeared for about a week. We didn’t know where he was, and I understood that his frustration was that he’s ready to have treatment, but the referral couldn’t come through. (R19)

This social worker, along with the PCT team social worker and the social worker from skilled nursing (R24), also noted that residential drug treatment admissions had been apprehensive about taking older people or those with any functional or cognitive impairments. Over half of the providers from across sectors emphasized the need for aging-friendly harm reduction and Housing First models that can provide on-site recovery services and long-term housing.

Jail

The nurse I interviewed currently working in the county jail (R26) had been in the homeless service sector for many years in case management, patient advocacy, and direct healthcare services. She explained how the nursing role initially felt “murky” because the jail was so “enclosed” from the rest of the care continuum, and shared what she had learned:

> The nurses all rotate through different posts-- there’s booking, of course…passing meds, doing triage, doing what they call nursing treatments which is following up on just basic things like vital sign checks, but that’s also where the wound care happens, and that’s all pretty much in the evening. And the nurses help the doctor and dental provider who come into the clinic.”

She added that the public health model of jail that made these services possible was nearly extinct; this county jail was one few remaining public-run correctional health programs (Gelman, 2020). Even in this public health model, she still felt limited in individualizing care, partially due to the “stigma and still conservative approaches to care for people who are incarcerated…like if you think somebody’s beyond rehabilitating, what is the point in treating them, right?” She shared that it depended on the officers and medical personnel that she was on shift with how much she could provide health education, explore treatment options, or even show compassion through body language: “I’m supposed to keep as much distance from people as possible in providing care, which is kind of new and uncomfortable." The variation in treatment was a trend that a forensic street outreach worker observed as well. They discussed their experiences advocating for provisional release:

> We have relationships with certain prosecutors who say 'yeah, we're not trying to keep this person with dementia in custody.' We see decisions that *I* would consider a no brainer. But I work with someone in permanent supportive housing with lot of health issues like brain injury, stroke, incontinence, caregiving services. She just got picked up on an old warrant and was in jail for a week. It was bad-- she was falling, she got an infection, it was really bad. Ultimately, she was sent to the hospital and got provisional release from there for medical reasons. But it was hard to imagine what her week there looked like because she had daily caregiving. Who's in here taking care of this woman? She was very traumatized by the experience… it's a mix and I am still surprised sometimes by people who are kept in custody, when really, they have this housing and this care team that could be supporting them outside. (R12)

The nurse in jail health illustrated through several case examples what kind of barriers she faced in discussing goals of care during end-of-life. She shared two examples of men seeking compassionate release and asking for information about physician-aided death. She discussed how, while currently cognitively intact to plan and express their wishes, she is limited: "I just tell him, in a different setting, I could have more of a conversation with you about options, and unfortunately, I can't do that here" (R26). She went on to discuss how the jail is used as a place to transfer inmates to when they surpass the acuity needs that the state prison can accommodate. "I think there is kind of a very complicated attitude sometimes with the court system and with jail that's like, 'Oh, well maybe they'd be better served by staying in custody'", noted the street outreach worker (R12). They elaborated:

> Honestly, I've heard the same from clients, too. Certain clients are like, 'Oh, I got to stay inside and be in jail during the winter,' or something. It's a complicated liminal space, where of course we don't want people to be in jail, it's very traumatizing, and also sometimes, jail is kind of used as shelter and to get at least some bare bones medical care. (R12)

Jail and other carceral systems gave a visceral reminder of how complicated negotiating health, care and safety could be throughout the continuum of places interviewees discussed. When asked about ways these providers envisioned improved care, central to their answers was decarcerating the strategic plan for addressing homelessness, so that unhoused people— particularly those sleeping outside-- could have access to safe housing and medical care without it being interwoven with punishment, forcible detention, and limited agency in healthcare decision-making. The jail health nurse emphasized the impact that privatizing prisons has taken on public health inside of the prison system, and shared that for older adults in prison, that inmate-operated health efforts have shown to positively impact both those receiving and providing care.

Summary

Provider perspectives illustrated factors that may enable or prevent care that is congruent with patients' needs and wishes. Providers noted the general health benefits of receiving supportive housing after time in less-health enabling sleeping places. In supportive housing, residents have long-term relationships with staff and agencies. This creates opportunities to know residents' wishes and general health status. Staff can be flexible and are accustomed to being agile in the face of structural problems. Many supportive housing environments are trained to respond to harm reduction and trauma and may be highly literate in specialty medical care for diseases like HIV/AIDS.

Tiny Home Villages and motel voucher systems had similar facilitators to care. They offered private space with some storage, which decreased dispossession, can increase adherence to treatment plans, and offer opportunities for patient-directed care. Tiny Homes are modular and can be adjusted to meet individual access needs. There is relative autonomy in these spaces, where patients can have freedom of movement and have privacy. Many temporary accommodations offer peer support opportunities that were noted by providers. Hospitals, particularly among those who frequently visit emergency departments, can be a source of familiarity and constancy. While they are restrictive, patients demonstrate agency in their ability to self-discharge. In hospitals, there is a capacity to address health concerns, offer comfort care, and provide security and oversight. Medical respite programs also offer access to lower-acuity medical care and can offer a lower-barrier and longer-term place for patients who may need health monitoring or more regular care.

However, barriers across systems were aplenty. Partnership challenges between supportive housing and healthcare and aging services were emphasized, both because of lack of knowledge of available services and appropriate referrals, but also because of unwillingness or inability of healthcare and aging programs to work with supportive housing residents. There are access issues to how need is assessed for healthcare services related to resident trimorbidity. Staff strain and staff shortage, amplified by the pandemic, can create socioemotional and capacity barriers to providing adequate care to medically-complex residents. Eviction risk is increased by serious health problems and aging, and supportive housing tenants have less legal protections than those with serious illness living in market-rate housing. Similarly, low-income senior supported housing may not offer eviction prevention and protection services to the degree needed. Environmental modifications and response to maintenance issues could be expedited in both supportive and supported housing.

Providers noted the challenges in transitional housing and shelter supply. More autonomy in decongregated temporary housing, like hotel/motel vouchers and Tiny Homes, may also result in increased vulnerability of older or seriously-ill residents with other residents and may result in reduced response time in health emergencies or not enough care referrals. Emergency shelters have major accessibility barriers, including their geographic locations. There is a bottlenecking in shelters caused by the coordinated entry system. Because shelter users do not have a lease and because shelters are not often equipped for advanced illness needs, users are often sent to high acuity medical institutions.

Hospitals are not intended for long-term stays, particularly when patients no longer require acute medical care. Providers noted that discharge was often determined by patients leaving on their own accord, insurance companies or hospital administration encouraging referral out, and by eligibility issues in lower-acuity medical settings. Providers spoke to a complex relationship of care between unhoused patients and the hospital, in which hospital providers were limited in what they could do for patients beyond institutional walls. Providers also acknowledged a general lack of knowledge on interdisciplinary hospital teams regarding trauma-informed care and described unique situations in which they enacted harm reduction and respected potential trauma triggers related to medical care. Medical respite, while lower-acuity and intended specifically for those facing housing challenges, also faces challenges in caring for those with serious illness, who may be “in-between” types of care, or who may still not have a place to discharge to by the end of their allowed stay in respite. As places intended for punishment, jail health providers noted that with older adults and those with serious illness, their roles precluded the possibility of discussing goals of care.

CHAPTER 5

FINDINGS: A QUALITATIVE TYPOLOGY OF RESIDENTIAL TRANSITIONS AT END-OF-LIFE FOR UNHOUSED PERSONS

Given the heightened health and mortality risks and changing age demographics of homelessness, expansion of primary and specialty palliative care services is needed to meet the complex needs of people experiencing homelessness and serious illness. Much of the existing literature on the palliative care and end-of-life experiences of unhoused people is setting-specific, describing best practices and interventions in supportive housing, shelters, or healthcare locations, or only sampling from a specific site (Ko, Kwak & Nelson-Becker, 2015; Song, Bartels, & Ratner, 2007; Leung et al., 2015; Stajduhar et al., 2020; Hudson et al., 2016; McNeil, Guirguis-Younger, 2012). This is also true of many existing empirically-supported typologies of homelessness, which generate a typology from static conceptualizations of homelessness based on time (e.g., “transitional,” “episodic,” and “chronic” homelessness) (Kuhn & Culhane, 1998), geography (e.g., “urban” or “rural”) (Marr, DeVerteuil, & Snow, 2009) or location (e.g., “shelter homeless, “street homeless,” “formerly homeless”) (Williams, 2011). To successfully develop palliative care models for this growing need among patients experiencing homelessness and for those living within the housing care continuum, it is essential to understand where barriers manifest in care and how they impact end-of-life care trajectories. Thus, there is a need for research that supports a better incorporation of temporality into the lives of people experiencing homelessness through sequencing and longitudinal patterning which proposes models that account for factors beyond time and specific location. No known research has yet to follow homeless palliative care patients across the last months of their lives to understand changes in their health and housing needs.

The aim of this chapter is to describe the common residential typologies of palliative care patients experiencing homelessness or housing precarity. The primary research question was: what are the locations of treatment and transitions in housing experienced by unhoused patients receiving palliative care?

Descriptive Program Data

34.7% of patients in the sample were referred from hospital systems, and an additional 24.0% were referred from outpatient primary care providers. 9.3% of patients were referred from medical respite and 5.3% were referred from specialty healthcare providers (e.g., oncology, nephrology). The remaining referrals came from the homeless response system, including supportive housing (14.75%), street outreach (8.0%), and emergency shelters (4.0%). Cancer was the leading cause of referral, followed by chronic cardiovascular, renal, hepatic, and pulmonary conditions. Common comorbidities found in over 50% of the sample included substance abuse, musculoskeletal conditions, psychiatric conditions, and cardiovascular conditions. In addition to the referring diagnosis, patients had a median comorbidity rate of 5.

Overall, patients were enrolled in HPC services for an average of 19.74 months. Of this time, an average of 7.74 months were spent in the initial location where patients were enrolled in HPC. During palliative care services, patients spent an average of 16.63% of their enrollment, a cumulative 3.29 months, in the hospital. Of the patients whose death prompted discharge from services, 37.5% died in the hospital, 22.5% died in supportive housing, 17.5% died in a skilled nursing facility (SNF), 7.5% died doubled-up in the care of informal supports, and 2.5% died in temporary accommodation. 21.3%

were enrolled in hospice. Among the sample, there were no recorded patient deaths while living unsheltered. Among those who did not die while enrolled in care (n=35), 48.6% remained active patients; the rest were discharged while alive for reasons including: exiting geographic region (2.9%), declining further services (14.3%), stabilizing or meeting care goals (17.1%), or referral to another residential location or outpatient service that addressed the patient's psychosocial, medical, and daily care needs (28.6%).

Housing Typologies

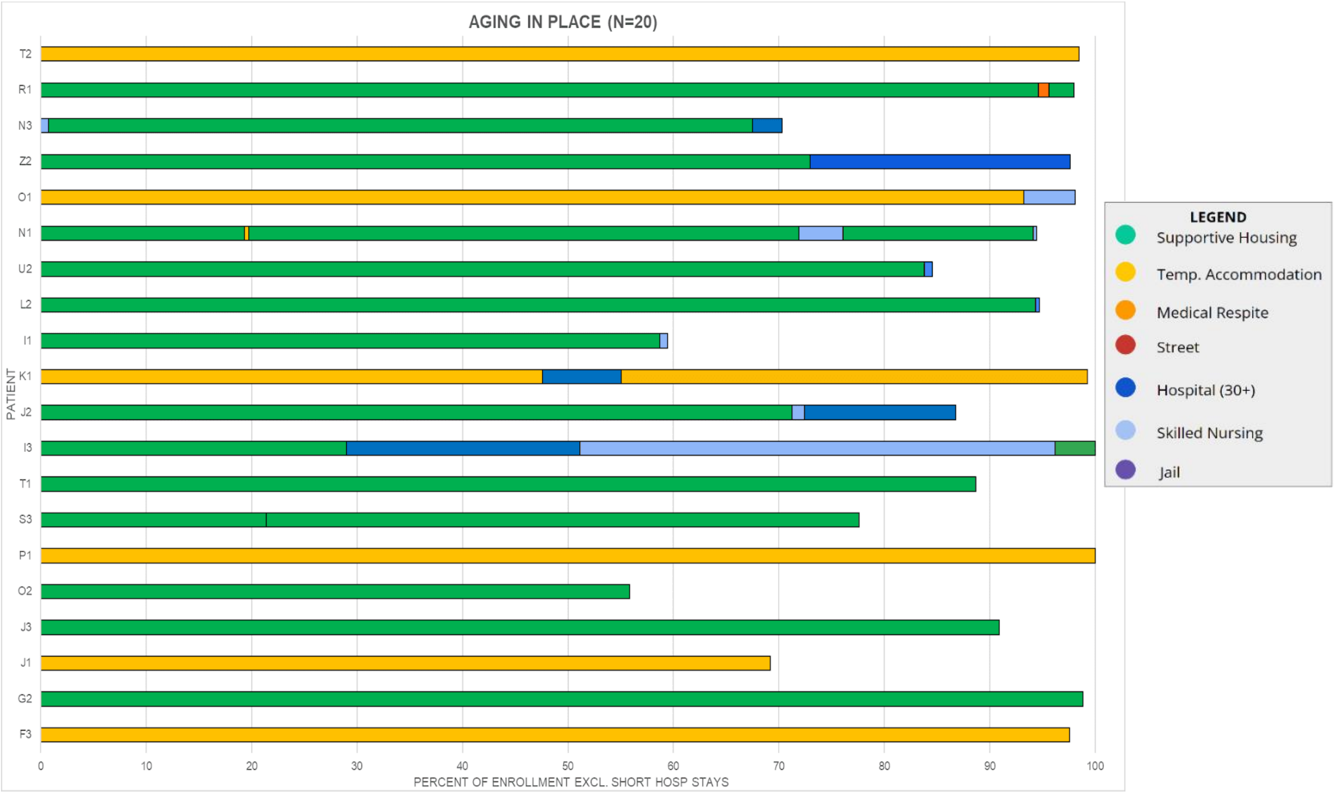
Based on the review of each housing transition of the 75 patients in this study, I developed a four-group typology of residential pathways during end-of-life for patients experiencing homelessness: (1) Aging and Dying in Place; (2) Frequent Transitions; (3) Healthcare Institutions as Housing; and (4) Housing as Palliation. These four groups provided an exploratory understanding of the importance of key variables in the trajectories of palliative care patients experiencing homelessness. Figures 5.1-5.4 depict individual residential trajectories within each group with the percent of their enrollment time spent in each place. For the purposes of legibility in these figures, hospitalizations under 30 days in which the patient returned to their prior location were removed.

Aging and Dying in Place

Twenty patients were in the Aging & Dying in Place typology (Figure 5.2). Eight patients had no residential transitions during their enrollment in palliative care services. One patient had a singular residential transition within their supportive housing agency, changing apartments to support their accessibility and care needs. Four patients returned to their same place of residence after long-term hospitalization, skilled nursing or rehabilitation stays, or stays with loved ones. An additional seven patients spent most of their enrollment in one place but died elsewhere. These patients were sustained in shelter or supportive housing settings for as long as possible and were then supported in end-of-life in more high acuity settings for fewer than 30 days.

Figure 5.1

Aging & Dying in Place



As a group, Aging and Dying in Place patients spent an average of 25.72 months enrolled in services. On average, patients in this group spent 18.08 months in the location they lived in when first enrolled in HPC services. They had an average 9.10 hospitalizations during their care, which accounted for 15.61% of the cumulative time each patient was enrolled in palliative care. The average number of residential transitions among patients during care within the Aging in Place typology was 1.75.

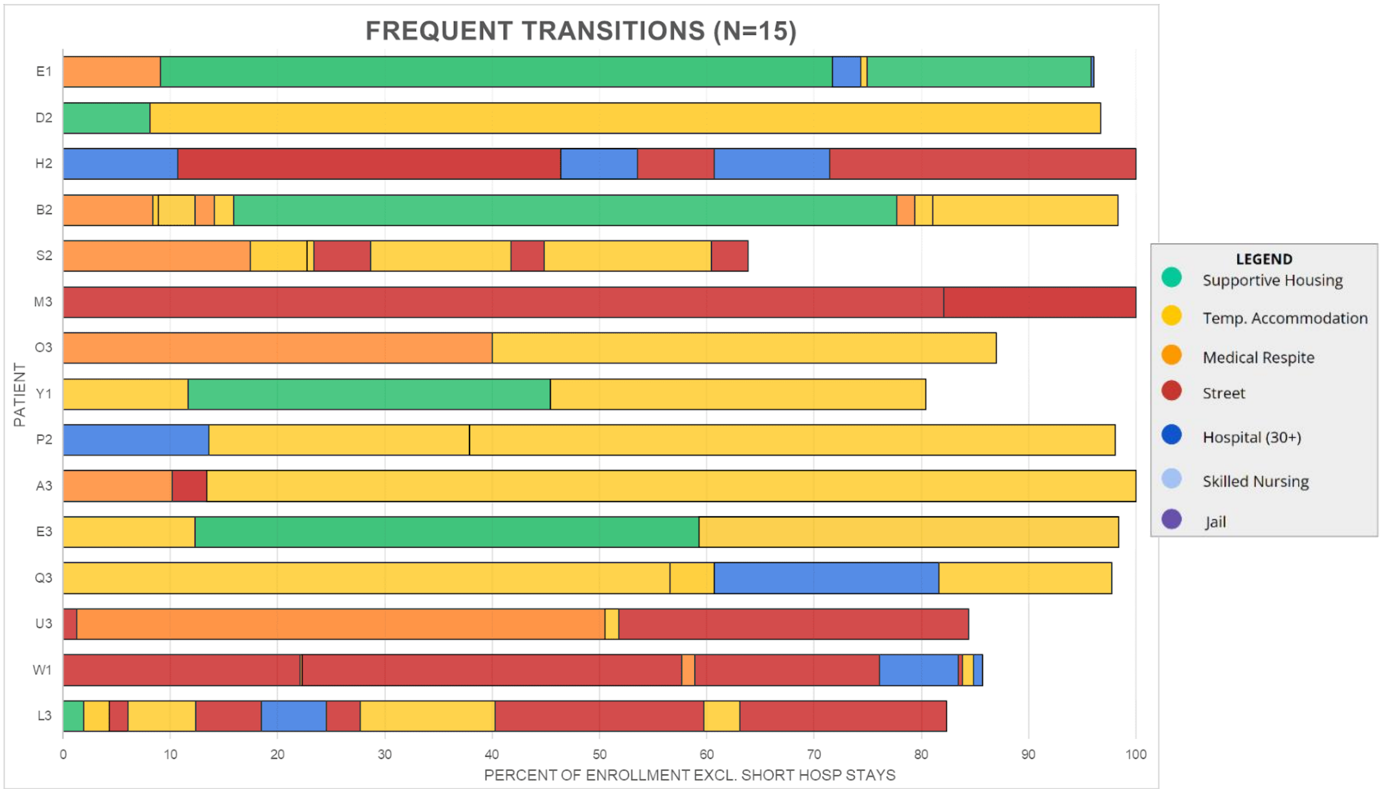
Frequent Transitions

The fifteen patients in the Frequent Transitions group (Figure 5.4) did not a obtain or maintain a consistent place to actively coordinate care during their enrollment in palliative care and spent less than 50% of their total enrollment within healthcare institutions. While six of the fifteen patients in this group accessed supportive housing at some point during the trajectory of their care, they exited and did not return to the same setting. Four of these patients were evicted from supportive housing for behavioral reasons (e.g., assault, hoarding or related behaviors, persecutory beliefs about housing agency). One of the six relocated for her personal safety because of intimate partner violence. Only one patient in this group moved out of supportive housing directly because of changes to physical health.

As a group, patients in the Frequent Transitions typology averaged 14.28 months enrolled in palliative care. Patients in the group averaged 6.53 hospitalizations within the course of their care and experienced a mean of 4.07 residential transitions. On average, patients in this typology spent 11.95% of their enrollment in the hospital.

Figure 5.2

Frequent Transitions

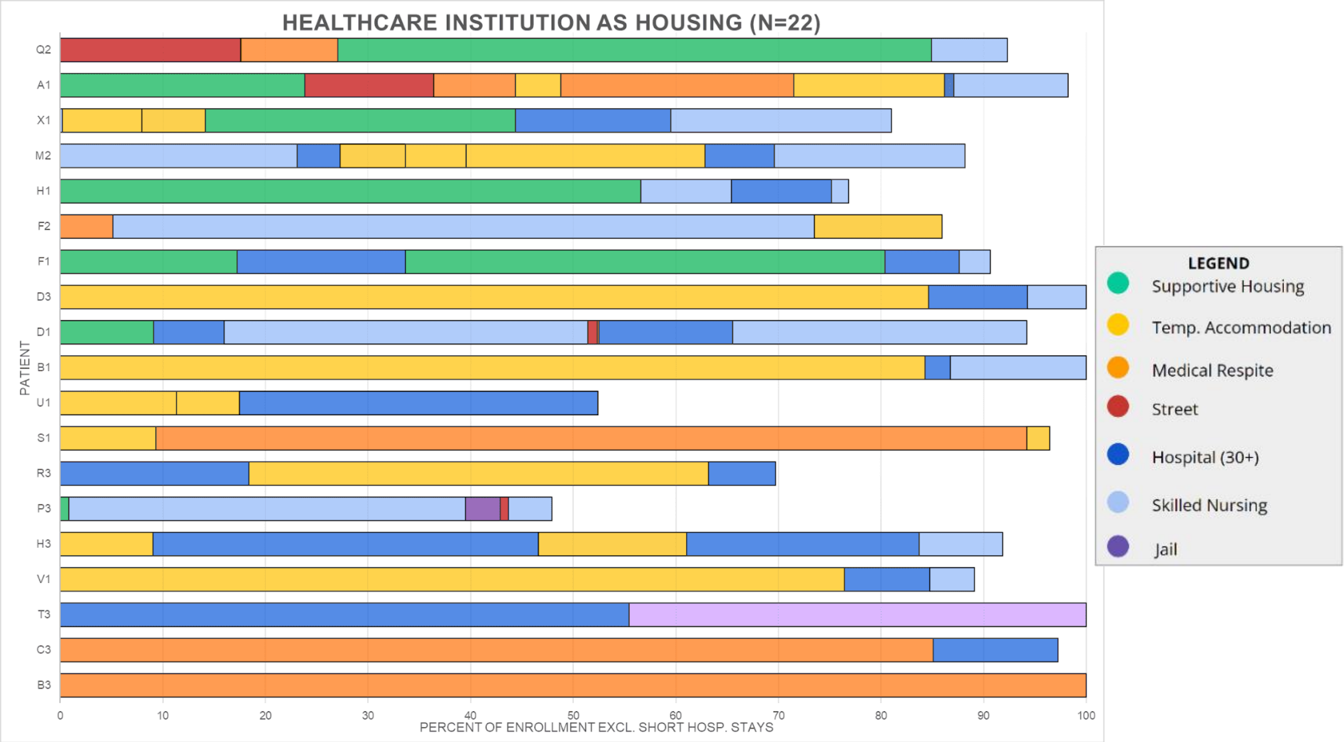


Healthcare Institution as Housing

Twenty-two patients met the criteria for Healthcare Institution as Housing (Figure 5.4). Four of these patients spent 100% of their palliative care enrollment in a healthcare institution or between multiple healthcare institutions. The average number of months spent at the patient's site of enrollment was 7.09, and the patients in this group had a mean of 2.68 residential transitions. This group had a mean length of enrollment of 16.63 months, and average of 5.91 hospitalizations during their palliative care enrollment. Unsurprisingly, patients in this group spent an average of 25.4% of their overall enrollment in the hospital. Notably, one of these patients was the only patient in the larger sample to be placed in an adult family home. There were five patients who spent between 50-99% of their total enrollment in palliative care within healthcare institutions; these patients had prior history of living unsheltered or used emergency shelters. Fourteen patients had at least one stay in a healthcare institution of greater than 30 days (hospital, skilled nursing facility, medical respite) and did not return to a previous location after that stay, most commonly because of a transfer to skilled nursing after a hospitalization. Six patients in this group left skilled nursing for either a long-term hospital stay or a brief residence in an emergency shelter, street encampment, or county jail, only to return to skilled nursing for the remainder of their enrollment.

Figure 5.3

Healthcare Institution as Housing

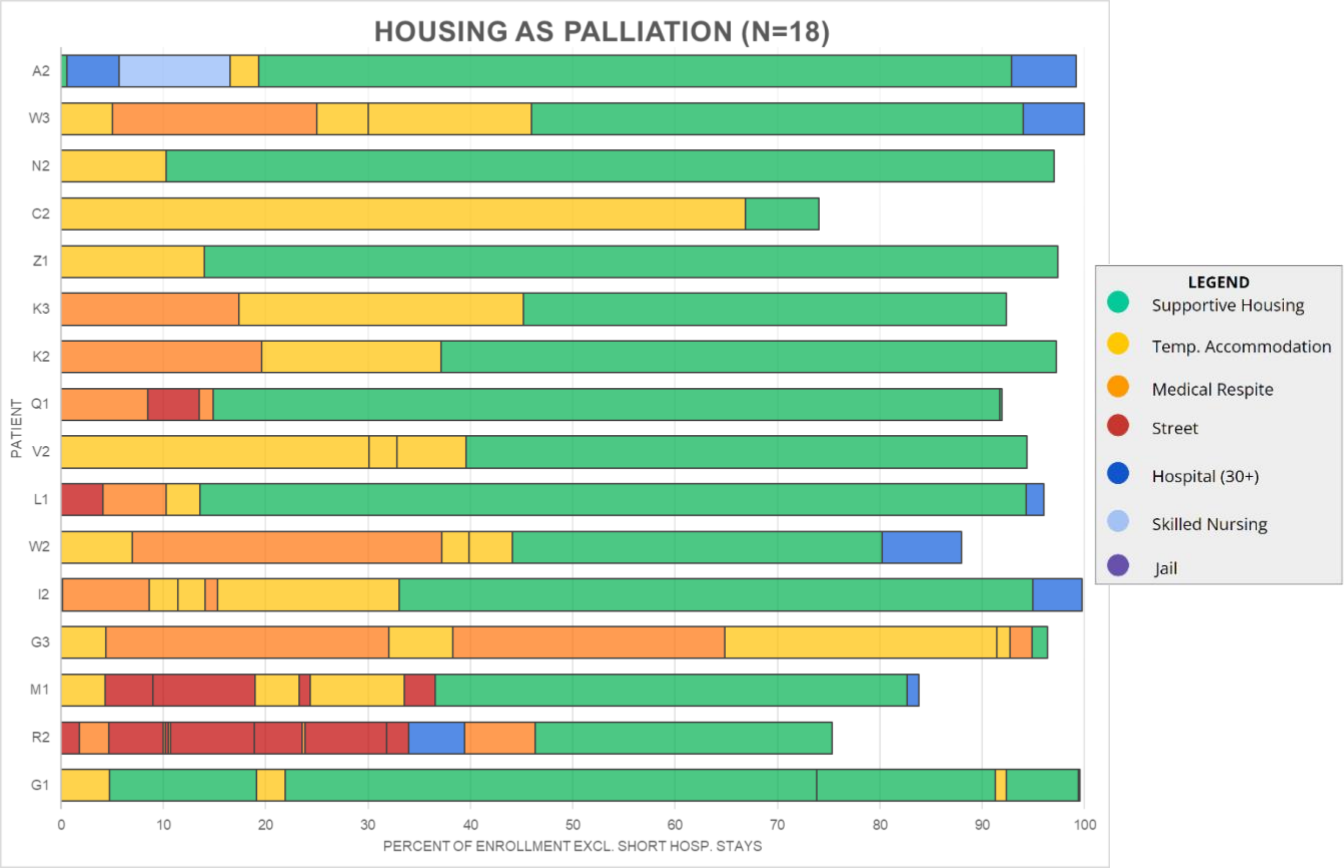


Housing as Palliation

Eighteen patients were categorized into the Housing as Palliation typology (Figure 5.5). All eighteen patients spent at least 30 days outside of supportive housing at the beginning of their palliative care enrollment, obtained housing through grave disability or other health-related mechanisms, and did not cease being a supportive housing resident before death/discharge. Patients in this group were referred to the team late in their illness trajectory, and some were discharged once housing was secured, as it sufficiently addressed their care needs. The patients in this group set obtaining housing as a palliative care goal, either for their own longevity and symptom management goals, or for psychosocial reasons such as meaning-making about having a home or being able to leave housing behind for a romantic partner. Their enrollment in palliative care services was 21.47 months. The mean number of residential transfers of the patients in the Housing as Palliation typology was 4.83 and the percentage of enrollment spent in the hospital was 10.96%. The Frequent Transitions typology's overall characteristics included a relatively short time spent in the place where they began receiving services (1.81 months) coupled with a high rate of residential transitions among the four groups (4.83).

Figure 5.4

Housing as Palliation



Comparison of Typology Groups

Residential and Healthcare Trajectories

A one-way ANOVA was conducted to compare each of the four typologies developed across five standardized variables about residential trajectory (Table 5.1). I used quantitative variables that matched with nodes in the decision tree (Figure 3.3), including length of enrollment, standardized rate of residential transfers during care, standardized hospitalization rate, percentage of days spent in first location per days enrolled, and percentage of days spent in the hospital per days enrolled. Tukey honestly significant difference (HSD) tests for multiple comparisons were completed for variables with significant between-group differences. I used an alpha level of .05 for all statistical tests.

Table 5.1

One-way ANOVA of Differences in Residential Trajectory Between Typologies

	Mean Months Enrolled in HPC Services	Mean Months in First Location	Mean Hospitalizations	Mean Residential Transfers	Mean Percent of Tx in Hosp
ANOVA *F*	2.07	13.63** [a,b,c]	.89	7.42** [a,b,e]	3.89* [d,e]
All Groups	19.74	7.77	7.45	3.23	16.63
Aging & Dying in Place	25.72	18.08	9.10	1.75	15.61
Frequent Transitions	14.28	2.20	6.53	4.07	11.95
Healthcare Institution as Housing	16.63	7.09	5.91	2.68	25.40
Housing as Palliation	21.47	1.81	8.28	4.83	10.96

*p= <.05
**p=<.001
[a] Aging & Dying in Place and Healthcare Institutions as Housing
[b] Aging & Dying in Place and Frequent Transitions
[c] Aging & Dying in Place and Housing as Palliation
[d] Healthcare Institutions as Housing and Frequent Transitions
[e] Healthcare Institutions as Housing and Housing as Palliation

Standardized hospitalization rate and days of enrollment were not significantly different between any of the four groups. Testing revealed that the mean number of months spent in the location of intake was significantly different between at least two of the groups (F=13.63, p=.000). Tukey's HSD test for multiple comparisons indicated that the mean months patients in the Aging & Dying in Place typology spent in their first location was significantly more than Healthcare Institutions as Housing group (1.01, SD .25, p=.001, CI .344-1.66), the Frequent Transitions group (1.45, SD .28, p=.000, CI

.720-2.18), and the Housing as Palliation group (1.49, SD .26, p=.000, CI .71-.78). The other typologies did not significantly differ from one another.

Also significant in this ANOVA was the residential transfer rate between groups (F=7.419, p=.000). Multiple comparisons testing showed evidence that patients in the Aging & Dying in Place typology average .94 fewer residential transfers than those in the Frequent Transitions group (SD .30, p=.02, CI (-)1.74-(-).14) and 1.25 fewer transfers than those in the Housing as Palliation typology (SD .29, p=000, CI -2.01—0.49). The Healthcare Institution as Housing typology had a significantly lower rate of residential transfers (-.87) than the Housing as Palliation group as well (SD .28, p=.02, CI -1.62—0.13). The Housing as Palliation and Frequent Transitions group typologies did not have significantly different transfer rates in their residential trajectories.

The standardized percentage of time spent in the hospital was significantly different between groups (F=3.89, p=.012). Patients in the Healthcare Institution as Housing typology spent 13.45% (+/- 5.0%) more of their time enrolled in palliative care in the hospital compared to the Frequent Transitions typology patients (p=.04, CI .25-26.64) and 14.44% more (+/- 4.76%) than patients in the Housing as Palliation typology (p=.02, CI 1.92-26.96).

Medical Diagnoses

There were no significant differences in number of comorbidities between groups. There were also no significant differences between typologies in the presence or absence of any specific diagnoses (Table 5.2). I omitted gastrointestinal and endocrine conditions from chi-square testing because both variables had a group size below 5. To further explore medical diagnoses, I created a variable for the presence or absence of trimorbidity— concurrent substance abuse, mental health, and medical health diagnoses. A chi-square test (Table 5.3) indicated no significant differences between patients with trimorbidity and those without (1.89, p=.60).

Table 5.2

Chi-Square Associations Between Typology and Medical Condition

	Total	Aging & Dying in Place	Frequent Transitions	Healthcare Institution as Housing	Housing as Palliation	Chi-Square
Cancers	49.3% (37)	27.0% (10)	27.0% (10)	27.0% (10)	18.9% (7)	2.725 (p=.436)
Chemical dependency	69.4% (50)	30.0% (15)	14.0% (7)	28.0% (14)	28.0 (14)	4.416 (p=.220)
Endocrine conditions	22.6% (17)	23.5% (4)	11.7% (2)	29.4% (5)	29.4% (5)	3.555 (p=.737)
Heart conditions	54.7% (40)	25.0% (10)	12.5% (5)	32.5% (13)	30.0% (12)	4.079 (p=.253)
Infectious diseases	34.7% (28)	28.6% (8)	17.9% (5)	32.1% (9)	21.4% (6)	.407 (p=.939)
Lung conditions	46.7% (35)	22.9% (8)	14.3% (5)	31.4% (11)	31.4% (11)	3.036 (p=.386)
Liver conditions	21.3% (16)	31.3% (5)	12.5% (2)	25.0% (4)	31.3% (5)	1.308 (p=.727)
Musculo-skeletal conditions	65.3% (49)	30.6% (15)	20.4% (10)	22.4% (11)	26.5% (13)	3.498 (p=.321)
Neurological conditions	44.7% (26)	38.5% (10)	23.08% (6)	26.9% (7)	11.54% (3)	4.918 (p=.178)
Psychiatric conditions	53.3% (39)	33.3% (13)	20.5% (8)	23.1% (9)	23.1% (9)	2.478 (p=.479)
Renal conditions	22.6% (17)	29.4% (5)	11.76% (2)	35.29% (6)	23.53 (4)	1.076 (p=.783)
Skin and wound care	34.7% (26)	34.6% (9)	15.4% (4)	26.9% (7)	23.1% (6)	1.460 (p=.692)

Demographic Differences

There was not sufficient diversity in the sample to test for cross-group differences related to veteran status, sexual orientation, gender identity, citizenship status, or primary language. I was able to run chi-square tests on binary variables for gender, generational cohort, age, and race/ethnicity (Table 5.3).

Table 5.3

Chi-Square Tests on Binary Demographic Variables

	Trimorbidity / No trimorbidity (n=75)	Under 65 years of age / 65+ (n=75)	Generation X / Baby Boomer (n=60)	Men / Women (n=74)	Black / White (n=61)
Pearson Chi-Square	1.89	5.47	.69	2.83	9.79
Significance (p)	.60	.41	.88	.83	.02 *

When chi-square tests of independence were performed on variables for gender (n=74), there were no significant discrepancies between which trajectory typology men and women were likely to follow (2.83, p=.83). The mean ages of the Aging & Dying in Place group (62.85 years) and the Healthcare Institution as Housing typology (62.36 years) were older than the Frequent Transitions (57.53 years) and the Housing as Palliation groups (58.94 years), but these differences were not statistically significant in a one-way ANOVA test. When categorizing the sample as 65 years of age or older vs. patients under 65 years of age, a chi-square test was still not significant (5.47, p=.41). Not all generational cohorts were large enough to run a one-way ANOVA inclusive of all patients sampled. When testing Baby Boomer patients and Generation X patients (n=60), a chi-square test did not indicate significant differences in trajectory typology (.69, p=88).

Regarding race, a crosstabulation indicated potential disparities for Black patients. When race is categorized into five groups (Black/African American; Latinx/Hispanic of any Race; American Indian/Alaska Native; Asian; White), only 1

Black patient (4.76% of all Black patients in the sample) were categorized into the Aging and Dying in Place Group, compared to 35.2% of the White patients in the sample. Conversely, 52.4% of Black patients (11) were sorted into the Healthcare Institution as Housing typology, compared to 20% of White patients in the sample. This difference was not statistically significant in a one-way ANOVA. When excluding other racial/ethnic groups (n=61), a chi-square test indicated that there was a significant difference between Black and White patients in which trajectory typology they were in (9.79, p=.02).

CHAPTER 6

DISCUSSION

In introducing this dissertation, I anecdotally shared how, as a social work practitioner traversing both institutional and homeless places, I came to adopt a stance against institutionalization as the best option for older adults facing housing precarity and homelessness. This stance is supported by much of the research from gerontology on aging and place, palliative care and end-of-life research surrounding site of care and goal-concordance, and homelessness research emphasizing restrictions to autonomy and removal of citizenship due to housing status. The universality of this goal is challenged by the limitations of current systems. We as social workers have great power in our ability to traverse worlds—we are invited into the lives of people we work with, and we operate as part of the system of "care" that is often corrupted with overt and covert demands to inflict state-sanctioned harm. The RASCAL-UP study puts forth an invitation for social workers and other allied health professionals to make mischief through an intentional and politicized movement between the two potentially-misaligned worlds of housing and healthcare.

Barriers & Facilitators of Care

When discussing independent low-income housing through rapid re-housing or grave disability, providers noted that success hinged on one's level of support and their fit with the environment. Providers saw older adults getting evicted from public housing into nursing homes, shelters, and to the street. One-third of renter households in the U.S. are over 65 years of age (Molinsky, 2021), and as urban redevelopment continues in most U.S. cities, low-income rentals and subsidized senior housing are dwindling (Perry et al., 2015). Eviction prevention for those with prior experiences with homelessness has proven to be most effective when combined with recovery services and primary medical care (Montgomery et al., 2016; Lee et al., 2009), as well as resources and support to reduce or prevent hoarding (Holl et al., 2016). Visiting case management and health support may make low-income senior housing or other public housing places more enabling of aging and end-of-life care.

Permanent supportive housing was sometimes an enabling setting that sustained PCT patients' care needs throughout their illness trajectories. Providers described the environment as one where staff wanted to assist residents and were aware of what knowledge they could offer health providers. In supportive housing and public housing, residents experienced relative autonomy and had access to supportive staff and neighbors.

Staff-level barriers to addressing aging and health issues included inadequate knowledge of available services, and spatial limitations to providing care and understanding care needs. Providers expressed not having the skills or ability to assess when hospitalization is necessary, and not having designated partnerships with tenant healthcare supports. Providers in the sample made recommendations for capacity-building, interdisciplinary education exchanges, and on-site healthcare provision. Providers noted the strain on the supportive housing system prompted by current coordinated entry tools, and by population aging without adequate integration of health services or innovations to housing models. In an environment with such immense strain, providers and systems may be prone to discarding or expelling those who are challenging to provide care for into medical institutions such as skilled nursing without sufficient consideration for resident needs and desires.

In temporary accommodations, such as single-room occupancies, hotels, motels, accessory-dwelling units and emergency shelters, staff noted that adaptability was a strength. In the context of Seattle, Tiny Villages were thought of positively by providers who mentioned them, PCT staff, and in patient chart documentation. Temporary accommodations like the Tiny Villages model may present itself as a politically marginal space with possibilities to facilitate resident autonomy and relationality in care. From the perspectives of providers, patient acceptability was notably high for motel vouchers and Tiny Homes because of their privacy, comfort, storage, and flexibility in supporting social and family needs, like caregiving, cross-gender cohabitation, and pet accommodation. Privacy in these settings not afforded in congregate settings like shelters, or informal social arrangements like doubling up, were valuable in achieving goals of care and preventing displacement due to concerns like incontinence. On the other hand, providers shared their observations of community and peer support in temporary spaces like shelters or Tiny Home Villages when it came to aging, end-of-life, and bereavement processes.

In temporary accommodations, interviewees illustrated a variety of vulnerabilities patients may face. There were accessibility challenges in shelters, notably sleeping and hygiene accommodations, hours of operation, and geographic location. Providers noted potential vulnerabilities older or seriously-ill shelter users may have with their peers and noted shelters and single-room occupancies were not always set up to protect older people from exploitation, theft, or violence. Multiple providers spoke of a “bottlenecking” that created a lingering in temporary accommodation. As peoples’ health and functionality decreased in temporary spaces, the fewer pathways there are to exit. Providers in temporary accommodations pushed for more training and awareness about what they do among health providers, built environment changes that honor access needs, increased capacity for hosting healthcare staff or volunteers, and policy reforms to expedite permanent housing placement.

The skilled nursing providers interviewed in this study were both specialized, one in veteran care and one in HIV/AIDS care. These providers may be outliers compared to skilled nursing and adult family home staff in their exposure to, knowledge of, and empathy for unhoused patients. These providers discussed several strategies for making skilled nursing feel like home for patients, including a focus on comfort and orientation toward patient-directed care. Same as with housing and homeless response providers, skilled nursing providers and medical providers who referred to nursing homes noted the “in-between”-ness of some patients’ needs. A nursing home may sometimes be too high-acuity at some point for patients, but they may be seriously lacking care access in other available settings. Providers also discussed the challenges of placing people experiencing homelessness into nursing care, even when it was the best option; providers noted stigma around mental illness, legal histories, and current or historical substance abuse. Further, patients with Medicare and Medicaid may offer low reimbursement rates for programs, which further disincentivizes placement in skilled nursing facilities or adult family homes. Geographically, many patients who are referred to skilled nursing are dispersed to unfamiliar environments out of the reach of their formal and informal supports. Providers shared their observations about skilled nursing and adult family home placements being unsuccessful due to patients’ needs for freedom of movement, personal agency over finances, and conflict with staff who are not trained in serious mental illness, trauma, or harm reduction. Skilled nursing closures and severe staff shortages were thought to amplify existing barriers.

Healthcare providers emphasized the complexities in unhoused patients' relationships to the healthcare system. Providers noted the potential for the hospital to be a place of fear, invasion, and restriction. Providers also noted that for some, hospitals can provide a potentially-overlooked sense of security and continuity of care. Providers noted that, particularly in public safety-net hospitals, emergency departments and specialty care health workers may build relationships with patients over the course of years and represent some of the most relational stability they have in later years. Because some patients do not have access to a safe discharge environment or an environment that matches their care needs, the hospital administratively must keep the patient, in which providers shared doing their best to build relationships, establish goals of care, and provide human comfort.

Ultimately, the hospital is not intended for residential care. The hospital was also well-documented as a site where patients' wishes may not be well-documented and respected. Inpatient providers noted that they are limited in what kind of psychosocial, emotional, and environmental support they can offer beyond their setting, particularly when residential service referrals can be such a challenge. Healthcare providers identified a need for increased incentives for skilled nursing to take Medicaid and dual-enrolled patients, enhanced flexibility in eligibility and maximum length of stay in medical respite programs for homeless patients, mobile and community-based care, and increased knowledge in working with patients with histories of trauma and in various stages of addiction recovery. Medical respite, while designed to be more long-term than the hospital, also has limitations in the amount of time they can provide support and what acuity of care they can provide to patients.

Providers did not identify facilitators to care in carceral systems outside of the setting addressing peoples' basic needs, like food and shelter. Providers relayed that both patients and representatives within the legal system alike sometimes posed this as justification for continued custody. This was contrasted by reports of the discrepant nature of compassionate release related to terminal illness or cognitive impairments like dementia. Due to healthcare privatization in prison systems, there was also an observed flow of aging or seriously-ill prison inmates back to public health-driven county jail; this is likely a unique feature of the area due to the rarity of public health programs in this setting (Gelman, 2020). A healthcare provider in county jail noted that, largely due to stigma and the conceptualization of incarceration as punishment rather than rehabilitation, health interactions with inmates is limited and not centered on patient goals. Providers suggested more harm reduction housing and respite options instead of mandated treatment, jail, or prison. Expedited provisional or compassionate release, de-privatized healthcare within jail settings, and formal opportunities for peer-to-peer caregiving were promoted as perceived needs.

Impact of Findings

The identified facilitators and barriers to the receipt of goal-concordant palliative and end-of-life care across systems illustrates how providers respond to aging, serious illness, and mortality within a broken safety net. Further, healthcare and housing are two divergent apparatuses without systematic pathways for referral, communication, partnership, or consultation. Supportive housing may offer an optimal site of aging and end-of-life care for people with histories of homelessness, especially those with trimorbidity. Housing First models that center harm reduction approaches to residential care, have shown positive outcomes in housing retention and healthcare utilization

(Baxter et al., 2019; Tsai, 2020), reduced jail time (Clifasefi, Malone & Collins, 2013), and improvements in resident perceptions of their own recovery and health management (Fentress et al., 2021). Housing First has not been evaluated in its facilitation of outcomes directly related to aging, palliative care and/or end-of-life.

While providers emphasized the need to embed and integrate healthcare into these settings, there may also be a tension in further medicalizing the supportive housing environment, as funding for such services may generate contingencies regarding eligibility, staffing, and deliverables that further distance supportive housing from its original mission as anti-carceral, consumer and peer-led (Boyd et al., 2016).

Researchers have established that receiving institutional care in a skilled nursing or medical space is undesirable among many older adults (Riedl, Mantovan, & Them, 2013), including unhoused older adults (Klop et al., 2018). For unhoused older adults, fearing institutional outcomes may be rational-- older people and those with serious illness are not provided dignified health and housing options without private insurance, financial support, or retirement savings (Huffman & Upchurch, 2018). Older people may face discrimination in skilled nursing settings that expose them to psychological and emotional harm (Kusmaul & Anderson, 2018), prompt aversion to formal care (Leyva et al., 2020), and result in lower quality of care (Travers et al., 2020). On a structural level, there is strain in every direction that demands that direct care providers and systems managers exceed their capacities or, conversely, to set rigid boundaries aimed at excluding and denying peoples' humanity and basic needs (Chadwick, 2014). The long-term care industry has lost $94 billion dollars in the first two years of the COVID-19 pandemic, resulting in nursing home closures that exceeded openings (American Health Care Association, 2021). Recent nursing home closures may add additional complication to existing restrictions to eligibility and barriers to goal-concordant care for patients with homelessness histories.

At the same time, providers in this study shed light on the nuance and complexity on how care is enacted in healthcare institutions. Providers in safety-net hospitals may come to know frequent inpatient service users well over the course of many years and be able to provide goal-concordant healthcare when they present to the emergency department or to specialty care encounters. Hospitals, rehabilitation centers, skilled nursing, and adult family homes may offer a sense of security to some, particularly institutions that have history interacting with patients experiencing homelessness. Regardless of if they are ideal or not, hospitals and nursing homes are a vital component to the current system of care for unhoused people; in a study of all those 55 years of age and older entering Boston's emergency shelter system, 12% were admitted to a nursing home within four years—nearly triple the rate of nursing home admission among the general older adult population (Byrne, Roncarati, & Miller, 2021). The rapid decrease in nursing home availability may pose increases in aging and serious illness in homelessness, housing, carceral, and healthcare systems without other residential care alternatives (McSweeney-Feld & Braunstein, 2020).

The drastic changes made to de-congregate emergency housing during the COVID-19 pandemic have spurred consideration for permanent changes that can be made to enhance health in temporary shelter accommodations (Scallan et al., 2022). Similarly, healthcare's COVID response has sparked thought regarding healthcare disparities and social determinants of health (Rollston & Galea, 2020), as well as contemplation surrounding the intent and implementation of past policies and procedures (Etkind et al., 2020). There is a window of opportunity currently to generate knowledge and pragmatic suggestions for de-congregated emergency and temporary housing.

Older people facing serious illness experience risks of displacement and dispossession while living unsheltered and in emergency shelter. Municipal legislation prioritizes the intended function of public places and the intended users of public place over any unexpected uses or marginalized users (Blomley, 2007). There are a multitude of legislative examples in which the physical appearance or anticipated behaviors of systemically-marginalized groups have been limited in public and semi-public places for the purpose of preserving the intended functionality or for attending to the intended users (Schweik, 2009; Loukaitou-Sideris & Ehrenfeucht, 2009). Carceral systems are suboptimal places of care. As Rankin (2021) proposes, current responses to homelessness represent punishment for public displays of poverty, disability, and mental illness. The disciplinary tactics are not only used by police and systems like the county jail, but within "compassionate" arms of the institutional circuit, enacted by social workers and healthcare providers in shelters, hospitals, and other places where people experiencing homelessness may go or be sent (Lopez, 2020), as well as in public places in the city (Rankin, 2021). Many patients in this sample have experienced housing instability long-term and survived years of movement through these systems of care; healthcare and social service workers provided perspective on how they, too, subvert punitive cultures in systems while caring for unhoused older people.

Care Trajectory Typologies

In this exploratory analysis of a theoretical sample of PCT patients, four typological patterns emerged from the data. The identification of four typologies in

Chapter 5 helps identify a subgroup of palliative care patients who were able to receive care in their supportive housing apartment.

Some patients achieved continuity of care during their enrollment in permanent supportive housing and in emergency shelter settings. While this group had fewer residential transitions during end-of-life and often died in a familiar non-institutional place, those who remained in supportive housing through their illness trajectory did not have significant differences in hospitalization rates compared to other groups. Patients in the Aging & Dying in Place group also had the longest periods of enrollment in care.

Some patients experienced frequent transitions throughout enrollment and did not establish a consistent and desired place of care during palliative care enrollment. This group spent more time unsheltered than other groups and spent less time in the hospital than other groups. The Frequent Transitions group had significantly more residential changes in their end-of-life experiences against all except the Housing as Palliation group, who established a place of care late in their palliative care enrollment. The Frequent Transitions group were also enrolled in palliative care services for the least amount of time.

This study identified a cohort of PCT patients who experienced long-term stays in hospitals and tenures in skilled nursing programs. The Healthcare Institutions as Housing typology indicated that some patients experienced hospitalizations longer than 30 days with frequency. Slightly less than half of patients in this typology ceased enrollment in palliative care while living in skilled nursing, or in one person's case, an adult family home. Some in this group also experienced movement in and out of different skilled nursing facilities. This group also utilized medical respite frequently. Patients in this group spent less time in the location they were first seen in at intake than patients in the Aging & Dying in Place typology. They spent a significantly larger proportion of their time enrolled in palliative care in the hospital—over one-quarter of their average of 21.47 months. Preliminary evidence outlined in Chapter 5 indicated that in this sample, Black patients were more likely than White patients to experience a trajectory of care characterized by long-term hospitalizations, skilled nursing admissions, and death outside of supportive housing or temporary accommodation settings.

In the last typology, Housing as Palliation, patients spent at least the first month of their enrollment unsheltered, in emergency shelters, doubled-up, in medical respite, or undergoing eviction procedures. These patients all secured apartments in supportive housing or low-income senior housing during their time in palliative care services, some through grave disability assistance. This group spent the least amount of time in the hospital, and largely died in a home setting. Those who did die in the hospital had relatively short final stays. One possible theory as to why those represented in the Housing as Palliation typology received housing later in care is that they were de-prioritized in receiving housing until later in their illness trajectory, given the ways that vulnerabilities are assessed and quantified in coordinated entry. They may have also become eligible for rehousing assistance as symptoms worsened or functionality decreased because of serious illness.

Impact of Findings

Permanent housing may an optimal setting for many older people with histories of homelessness and trimorbidity, even though siloed care and a lack of cross-specialty expertise create risk factors for tenants aging in supportive housing (Shalev et al., 2020). Studies have shown that permanent housing is a longitudinally cost-effective alternative to skilled nursing for people simultaneously experiencing homelessness and serious illness (Bamberger & Dobbins, 2015). Hospital and healthcare systems are increasingly engaging in addressing social determinants of health (Horwitz et al., 2020); permanent supportive housing operated by health systems have seen positive physical health outcomes and high tenant satisfaction with health supports (Palimaru et al., 2021). Housing First and other harm reduction services share a focus with palliative care, in that both center self-determination and quality of life, and have similar ethos regarding balancing risk with patient choice (McNeil et al., 2012). Findings in this study also indicated that some patients were able to establish continuity of care while living in emergency shelter settings. Existing research notes that those 65 years of age and older, and those with disabilities have longer stays in shelters (Hao, Garfield, & Purao, 2022). The socioemotional experience of living in the shelter in older age and during end-of-life has been illustrated as complex, one of both hope and grief (Burns et al., 2018) and one in which feeling “in-place” vacillates (Burns, 2016). Further research is warranted to explore first-person perspectives on desired place of care. Given the established benefits of mobile healthcare partnerships with unhoused populations (Pottie et al., 2019), the impact of PCT involvement in care with patient outcomes is necessary in both supportive housing and shelter settings.

In the subset of patients who fit the Frequent Transitions typology, patients moved between sanctioned and unsanctioned encampments, Tiny Home Villages, emergency shelters, informal care settings, jails, sobering centers, and residential substance abuse treatment. This group did not establish concordance between a desired and actual place of care during palliative care treatment. Expulsion is an established type of forced mobility in the lives of people experiencing homelessness (Kaufman, 2022). Disabled and older people experiencing homelessness may simultaneously be especially affected by municipal strategies to confine homelessness (Johnson, 2022). Forces of expulsion and confinement create an environment where there are narrow opportunities for establishing stability in a place that facilitates patient's health goals. Shelter systems, even those with embedded health supports and low-barrier policies, continue to face accessibility issues and elevated social and environmental risks for older and chronically-ill users. In the wake of COVID-19, the drawbacks to congregate temporary accommodations have been underscored. In this study, providers were emphatic in their support of decongregated low-barrier emergency and transitional housing. Such decongregated spaces may prove particularly for patients like those in the Frequent Transitions group, who may have less familiarity with the experience of homelessness or housing loss (Humphries & Canham, 2021), and/or histories of institutional trauma or aversion to formal services (Scutella, Wood, & Johnson, 2021). The social networks of people experiencing homelessness are directly impacted by geographies and experiences of homelessness, as well as the limited material resources and sociopolitical burdens on those networks (Cummings et al., 2022). Informal caregivers in the United States are under-supported in financial incentives (Ornstein et al., 2017) and in supplemental community-based formal caregiving services (Kumar et al., 2020), a factor that drives incongruence between desired and actual place of care among housed people (Glass, 2016).

In the last two decades, the overall percentage of deaths that occur in hospital and nursing facility have declined (Cross et al., 2020). Through the identification of the Healthcare Institutions as Housing typology, it can be speculated that interventions aimed at facilitating care and site of end-of-life elsewhere may not reach homeless or housing-precarious patients. Among palliative care patients with serious and chronic illness, risk factors for hospital death included being younger in age, having more co-morbidities, and receiving less outpatient care (Hicks et al., 2018)—all of which may be attributes of seriously-ill people experiencing homelessness. While adult family homes may offer a less institutionalized place to receive higher-acuity care, established barriers to end-of-life care include alignment and fit with patient values, reliance on communication with resident's informal caregivers (Washington et al., 2018). Those who are homeless at end-of-life may face a host of stigmas, may have end-of-life wishes that do not align with dominant cultural values, and may not have available formal and informal supports outside of adult family homes to sustain care and residence. Kushel (2018) provides initial evidence that patients experiencing homelessness have a much higher likelihood of being discharged to a nursing home than to lower levels of care, and that said patients have longer stays in rehabilitation and skilled nursing despite lower-acuity needs. The RASCAL-UP study provides further indication that discharging unhoused patients from the hospital is often a matter of medically stabilizing someone enough to return to an inadequate place of care within the homeless response system or making a case to place someone in a highly-restrictive institutional care environment when it may be less desired and less necessary than community-based options.

Initial evidence suggests that there are racial disparities in which patients experience long-term and/or unreversed residence in healthcare institutions. There are well-documented differences in both hospice access (Bazargan & Bazargan-Hejazi, 2021) and acceptance (Mayeda & Ward, 2019) between Black and white patients. There may be cultural and spiritual root causes for intentionally pursuing longevity and life-sustaining treatment among non-Hispanic Black patients in the United States (Branch et al., 2006; West & Levi, 2004). There may also be a refusal for Black people in being "full code" within the context of the racialized sociopolitical production of disability and death (Elbaum, 2020). For all these reasons, the hospital may be the most equipped to provide care congruent with patient wishes. At the same time, older non-Hispanic Black people still by-and-large still prefer end-of-life care to take place beyond institutional walls (Barnato et al., 2009). For Black and Latinx older people, the presence of informal supports is a mediator in determining the ability to receive end-of-life care at home (Orlovic, Smith & Mossialos, 2019), but the social supports of people experiencing extreme poverty are also facing occupational, financial and health burdens that limit the kind of support possible (Mickelson & Kubzansky, 2003).

The fourth and final typology identified in this research study, Housing as Palliation, provided insight into the potential housing benefits to specialized healthcare. Mobile health interventions are positively associated with exits from homelessness and are generally found to be acceptable by homeless populations (Moczygema et al., 2021). The identification of this group who received housing during PCT care also may point to flaws in the vulnerability assessments now woven into coordinated entry. Research has established the link between healthcare utilization and medical treatment adherence and housing retention, for both general populations (Luppa et al., 2010) and Housing-First supportive housing tenants (Collins et al., 2013). It is suggested through this study that the sooner seriously-ill patients can receive housing post-diagnosis and prognosis, the more positive treatment outcomes may be related to goal concordance, quality of life, and comfort measures.

Implications

Planned efforts in American cities to “end homelessness” have not worked because they operate from an assumption that homelessness is a result of individual-level problems that can be alleviated by the provision of shelter and resources (Anderson et al., 2022). It is the responsibility of social workers to collaborate in action with people facing housing loss and displacement to work toward long-term solutions (Belcher, DeForge & Zanis, 2005). In the meantime, social workers and allied health professionals serving unhoused people with serious illness must contend with and work within the contemporary realities of two broken systems that do not communicate effectively with one another.

Practice

Healthcare Systems

Training and education were seen as an essential need; housing and homelessness service providers wanted healthcare providers to be more familiar with their capabilities and limitations. Healthcare providers, particularly social workers in healthcare settings, noted an interdisciplinary need for training on how to provide trauma-informed, patient-centered care that was informed of histories of homelessness, active substance use, mental health difference, and physical disability. Emergency shelter staff’s ability to facilitate and recruit health-affirming programming has shown promising initial outcomes (Kendzor et al., 2017). Some research literature has suggested that eldercare institutions integrate alcohol and drug assessments and harm reduction strategies in medication management (Johannessen et al., 2021), or have engaged community-based senior services in homelessness prevention (Crane et al., 2006). However, there are fewer known existing interventions focused on educating aging services and healthcare professionals on the housing care system or improving their responsiveness to the needs of people experiencing homelessness. There are important distinctions to consider when supporting aging and end-of-life with people experiencing homelessness, such as family estrangement, financial limitations, and substance abuse and recovery, that will be necessary to consider in adapting existing training (Sumalinog et al., 2017). Healthcare providers and their care recipients may benefit from specialized training focused on the psychosocial, emotional, and spiritual experiences of older people experiencing housing loss. Incorporating healthcare for the homeless into professional education curriculum may better prepare and entice emergent health professionals to take up available positions within the homeless response arena (McLeod & Walsh, 2014).

Housing System

Housing and homelessness service providers needed more training and education on aging processes, health issues, and palliative care and end-of-life. Families and next of kin with various levels of engagement with older people with trimorbidity can benefit from social workers and other health professionals in aging and long-term care services who are well-versed in the specific issues they face surrounding healthcare decision-making and site of care (Morgan, 2016; Padgett et al., 2008).

Capacity-building efforts to enhance and prolong community living in supportive housing for older adults is already underway. Tenant-facing interventions such as the Stanford Chronic Disease Self-Management Program (Henwood et al., 2013) or Functional Adaptation Skills Training (Pratt et al., 2008) have shown to be effective at improving older supportive housing tenants' self-perceived health and health and housing outcomes. The Do It Your Way program (Foti et al., 2003), a curriculum built for internal training, has shown promise at successfully empowering supportive housing and outpatient mental health staff in managing aging, chronic health conditions, and end-of-life. On the provider side, the Integrated Mental Health and Palliative Care Task project was created for nurse practitioners to better understand trauma, addiction, and serious mental illness; this model could be adapted and tested for use in interdisciplinary education and collaboration between homeless response and healthcare providers (Taylor et al., 2012). Existing evidence-based training programs for improving serious illness communication, such as Vital Talk, could potentially be adapted for housing care continuum providers (Arnold et al., 2017).

Due to economic restrictions, stigma surrounding mental illness and substance abuse, and capacity limitations, there are no current places where older adults experiencing homelessness can have their longitudinal health and housing needs met. Supportive housing programs have made attempts in recent years to increase the capacity for aging and medical care needs within existing housing models. As suggested by providers in this study, increased medical staffing in supportive housing and more mobile health services geared toward housing-precarious and unhoused older people could enhance current care models. Supportive housing may benefit from the integration of community-based long-term care programs such as Program of All-Inclusive Care for the Elderly, a Medicare/Medicaid service packages that offers wrap-around support for older adults. There are toolkits for developers and property managers on how to support healthy aging in the setting (Corporation for Supportive Housing, 2016), but no known research studies explore their implementation. Co-located healthcare and case management services within public housing may decrease eviction or other forms of forcible displacement.

Aging & Disability Systems

Social participation through volunteerism and civic engagement is the cornerstone in the post-retirement experiences of many older adults (Serrat et al., 2020). Providers, particularly those working with Tiny Home initiatives, emphasized the need for the surrounding neighborhood and community to be engaged in mutual aid and care networks of temporarily-housed older adults. Volunteer programs such as MAUVE + ED (Ellis et al., 2020) have seen to be effective in supporting both older adult volunteers and older adults facing hospitalization and housing precarity. However, the bureaucracy surrounding homelessness response can squash community-based action efforts led by older people (Westneat, 2022). Places with access to stably-housed and time-resourced older adults, such as senior living communities or senior centers, may consider how to support mutual aid and eliminate barriers to volunteerism. Aging & Disability Services and Age-Friendly municipal programs could better outreach the spectrum of housing care services to increase and enhance coordination.

Policy

Healthcare Systems

Providers across the country have advocated for more mobile health services for homeless older people, in part due to its overwhelming acceptability among patients (Fazel, Geddes, & Kushel, 2014). While palliative care services specialized for patients experiencing homelessness have recently spread in Canada (Schneider & Dosani, 2021), the PCT remains the only mobile palliative care team for homeless communities in the United States. The PCT, all part-time, receives a significant portion of its funding in “soft money” from philanthropic groups outside of the United States. The funding portfolio of the PCT is a glaring reminder of the inaction regarding the inequities that pervade end-of-life care in the United States (Wachterman & Sommers, 2021) and limit site of care for poor people in urban (Gramelspacher & Gunderman, 2018) and rural places (Cai & Lalani, 2022) alike. The exploration of PCT patient trajectories and narratives from the providers they've interfaced with since their inception gives preliminary insight into the potential impact that mobile palliative care models can have for patients experiencing homelessness and housing precarity. Funding to sustain and expand specialty homeless palliative care services is essential in the context of homeless population aging and overwhelming service gaps for poor people with serious illness. In the coming years, it is likely that Medicaid and Medicare will increase coverage and billability for outpatient and home and community-based palliative care services. It is essential that the policies and procedures developed in the process are inclusive of people with unconventional living arrangements and are proactive about addressing potential disruptions in care caused by changes in location. State policymakers can improve community-based palliative care delivery for Medicaid beneficiaries by more clearly articulating coverage and payment policies (National Academy for State Health Policy, 2019). In a political and geographic context in which so many people with serious illness cannot access services, the PCT model may be adaptable in devising specialty mobile palliative care outreach to other populations, such as Medicaid/Medicare and uninsured patients in rural areas.

A clear common need across service sectors was a need for new low-barrier housing interventions with on-site medical and nursing care. Providers specifically wished for hospice residences, skilled nursing, and assisted living programs that accommodated the psychosocial or behavioral barriers that skilled nursing couldn't, and the medical and health needs that supportive housing wasn't staffed or built to do. The continuing care retirement community (CCRC) model allows access to multiple levels of care on one campus but are generally cost-prohibitive and geared toward older adults with different lived experiences than those accessing the housing care continuum (Zarem, 2010). Specialized long-term care has been developed for those with issues unhoused older adults might face, including alcohol-related brain injury (Rota-Bartelink, 2006) and addiction (Serge & Gnaedinger, 2003), but are there are no known current programs like this in the United States. Brick-and-mortar hospice residences for patients with lived experiences of homelessness are similarly scant (Health Communication Research Institute, 2022). Programs such as these are unlikely without policy reform that incentivizes skilled nursing programs to refine their admissions criteria and residential procedures to be more accommodative, or to offer comprehensive specialty behavioral and mental health resources on-site. Incentives for adopting Culture Change designs, procedures, and organizational policies in skilled nursing and memory care may also address the socioeconomic inequalities seen in disparate resident freedoms and rights.

Safety-net healthcare systems may assume more risk in value-based reimbursement structures, where pre-existing health conditions of the system's patients may influence how value is measured (Chin, 2021). On the other hand, value-based reimbursement has prompted increased investment in hospital systems addressing social determinants of health (Horwitz et al., 2020). The economic environment produced by valued-based care may offer opportunities for expanding healthcare institutions' investments in housing, education, employment, food security, transportation, and other community-based innovations (Horwitz et al., 2020). Such investments are rife with risk of redirecting money away with community-based and community-led organizations (Taylor, 2018), a problem that may be avoided through partnerships between healthcare institutions or through the direct allocation of funds to organizations with histories of trust with and involvement from community-dwelling older adults and people with disabilities.

Housing Systems

Environmental design shifts in shelters have offset barriers to shelter stays (Davis, 2004). Built environment considerations in temporary accommodations need to be made to improve the health and safety of older people, as well as the potential social needs of aging constituents. This can be made a requirement under the Americans with Disabilities Act or through municipal- or state-level policies or could be federally incentivized for shelter operators. Tiny Home Villages offered a low-barrier site of care, in part due to its modularity. Tiny Homes have been supported both as a transitional intervention (Ford & Gomez-Lanier, 2017) and an effective affordable permanent housing strategy (Jackson et al., 2020), and according to the providers sampled, show acceptance and feasibility among older adults with complex health needs. Cost has been an implementation barrier in Tiny Home Villages (A-Mark Foundation, 2022), and city-operated villages have begun to enforce punitive and restrictive policies that may prevent them from filling a gap in care (Plotnikova, 2022). Exploring Village models supplemented with on-site or visiting health services may be a worthwhile future direction for programming and research.

Interview discussions of the VI-SPDAT were unanimously negative. Providers in this study backed research arguments that have been made regarding the VI-SPDAT's inability to measure intersectional vulnerabilities (Cronley, 2020). Providers also noted that coordinated entry had prompted bottlenecking in both shelter and supportive housing settings, and staff and system strain caused by changes to the makeup of supportive housing buildings. Coordinated entry assessments can be improved to acknowledge aging and disability in a more comprehensive and intersectional way.

Aging & Disability Services

Contemporary advocacy demands such as the passage of legislation supporting medical and family leave, childcare parity, increased investment in Medicaid Home and Community-Based Services, and paid informal caregiving programs can provide homeless patients' social networks with services to make "doubled-up" informal care more possible (Caring Across Generations, 2022). Supportive housing partnerships with Program of All-Inclusive Care for the Elderly (PACE) programs, or other supportive housing models that allow for high levels of intervention, may also be considered toward equity.

Municipal initiatives to make public places in cities "friendly" for aging and disabled citizens must take an equitable lens to who is considered (Greenfield, 2018)—for example, age-friendly approaches to increasing neighborhood safety or sidewalk accessibility should not come at the price of forcible displacement and dispossession of unhoused older and disabled people living in encampments without a suitable and acceptable referral to temporary housing. Reorienting age-friendly and disability-friendly initiatives requires centering accessibility and quality of life over mitigating the costs of older adults on public systems (Joy, 2018).

Limitations

There are several limitations that are important to note. There are racial and ethnic groups with a disproportionately high rate of homelessness locally who were unrepresented in the sample. Theoretical sampling efforts can be made in the future to include Native Hawaiian and Pacific Islander people experiencing homelessness, particularly as there is limited existing research on unhoused older and/or seriously-ill Native Hawaiian and Pacific Islander people. Homelessness is a localized issue, and the generalizability of this study may be limited due to differences in municipal and state funding, legislation, and response strategies, as well as local history and geography. Not only are there qualities specific to this city worth considering, but the study may not have valuable contributions in considering rural homelessness and aging or serious illness—this was outside of the intended scope of this study's design but is also largely underdeveloped in research and practical service knowledge.

I was unable to run statistical analyses to assess differences between most socio-demographic factors due to inadequate sample size. Theoretical guidance suggests there may be associations between some variables whose null hypotheses could not be rejected at this time. Future chart review analyses of patient charts of the full sample of PCT patients may assist in testing exploratory theory and further developing translational science aims.

In interview sampling, I ran into barriers recruiting interview participants in residential drug treatment programs and nonspecialized skilled nursing facilities. While these service sites may be on the periphery of the care network supporting older adults experiencing homelessness, the analysis and discussion of the capacities and needs of those places is limited without perceptions from providers working within those settings. The use of PCT charts and provider narrative to inform outreach may have created bias in the sampling strategy. Interviewing as a form of data collection requires an interpretive analysis of language, tone, and affect— this information is filtered through my lens as the researcher. My experiences both as a former social service provider within homelessness, aging and mental health arenas, as well as my own privileges and history of material and social hardships, influence how I behaved in relation with my interview participants and analyzed and made meaning from data.

Due to COVID-19's restrictions on data collection during this dissertation period, first-person narratives of place and space experiences during palliative care were not accessed in this project. When relating to one another laterally, we can focus on futurity— mutual envisioning of the future is an act of sovereignty from existing systems of power far more threatening than resistance (Ferguson, 2015). In future extensions of the RASCAL-UP study, I intend to address this flaw in research design by collecting interview and observation data directly with patients and incorporating a patient advisory board as coresearchers (Redman-MacLaren & Mills, 2017).

Future Research

The exploratory identification of a four-point typology for palliative care patients' residential trajectories can be useful for future research. In future research, testing this typology with a sample inclusive of the entire PCT roster may help verify or further clarify themes and patterns. This is a novel team; exploring how enrollment in PCT services effects trajectory may be explored by comparing this data set to a local sample of palliative care patients not receiving services. While no patients in the PCT sample were known to have died on the street, King County Medical Examiner (2022) reports that in 2021, 133 people presumed homeless died in shelters, hotels, doubled-up, in vehicles, and on the street. COVID-19 is believed to have caused more than double the deaths on the street in San Francisco (Cawley et al., 2022). City and hospital data may illuminate the effect of PCT enrollment on residential trajectory. Future directions in further attending to inequities in palliative care with patients experiencing homelessness could include larger scale data collection methods and multi-site comparisons. Purposive theoretical sampling in this research may enhance understanding of how race, gender, citizenship, sexual orientation, veteran status, and disability could impact residential trajectories.

Particularly in the case of the Housing as Palliation group, subsequent research must be done on if this outcome is a specific result of this model of care's involvement or is achieved among those not receiving this unique service. Residential trajectories, among other patient outcomes, may be useful in developing translational research that explores the PCT model's potential in other locations. Further testing of the PCT model could lead to exploration of the acceptance and feasibility of a mobile model with other populations with serious illness, such as older adults in rural communities, migrant workers, and in the aftermath of climate-related events.

Because of its relative facilitation of tenant autonomy, harm reduction approach, and existing capacity to conduct trauma-informed care with previously-unhoused populations, supportive housing may be the best place for many patients to receive palliative care and hospice services. Capacity-building, training, and education can be challenging with workers who are experiencing burnout and exploitation (Chadwick, 2014), so future research may explore how to build or adapt incentivized certificate programs within supportive housing to increase provider knowledge, comfort, and support in working with residents on issues related to aging, illness, and end-of-life. Palliative care consultation models may be useful for housing agencies and could be further explored in translational research. Healthcare professionals may also benefit from receiving specific training about substance abuse and recovery, trauma, experiences of homelessness, serious mental illness, and housing resources and assistance. Research may explore training and capacity-building with healthcare professionals as well.

Interviews with providers across a wide variety of service models allowed for a deep consideration for the strengths and barriers in various housing models. Temporary housing is intended to be a low-barrier access point to permanent housing solutions. Exploring acceptability of temporary accommodation models among people with complex medical conditions, as well as other stakeholders such as housing staff, housing administration, visiting healthcare provider, may provide a start. Two models of temporary care that warrant further research investigation in the immediate future are medical respite and Tiny Villages. Research can further investigate the use of medical respite for chronic illness management, as it is designed to support more acute and temporary health conditions. An evidence-based Tiny Village toolkit may assist in expanding the capacity to facilitate access for older and/or disabled tenants, particularly as the model gains in use and popularity among both non-profit supportive housing agencies and mutual aid groups (Luoni, 2019).

For all the plans to solve, fix, and end homelessness, there are a sparse few who call upon the voices of actual housing service consumers to guide the way forward (Sparks, 2012; Phillips & Kuyini, 2018). Future research can employ participatory action methods to mapping and design. An early step in this process may be employing older tenants to envision what a specialized care in supportive housing could and should look like. First-person narratives (or counter-narratives) from older and seriously-ill unhoused people about how they relate to place can expand the ways we design and imagine care.

Conclusion

This study accomplished two primary aims: (1) illustrating the barriers to accessing care across the many intertwined systems that unhoused palliative care patients face; and (2) developing an exploratory typology to describe residential movements of palliative care patients throughout treatment. Addressing these two aims simultaneously allows for some preliminary theorization on how housing care continuums and healthcare institutions may be able to enhance congruence between desired and actual place of care with palliative care patients experiencing homelessness. The RASCAL-UP study provided initial insight into previously unresearched novel program for palliative care delivery with people experiencing homelessness.

This study offers summative narratives detailing the opportunities and barriers facing providers in their care for unhoused older adults. The care workers who staff our hospitals, homeless shelters, clinics, housing, and our sidewalks have developed an understanding of the cracks in the systems of care for unhoused people with serious illness, many of whom are Baby Boomers. Four specific residential pathways were identified in patients receiving palliative care while homeless. Those aging and dying in place within supportive housing, emergency shelter, and extended-stay hotels, those with a reliance on healthcare institutions for housing, those who experienced frequent residential transitions during care, and those who become housed later in their illness trajectory may all have unique, specialized needs. These four pathways lay the groundwork for targeted intervention design and implementation in specific settings, including capacity-building and training in supportive housing, the design or redesign of models of care intended to be strictly rehabilitative, and robust mobile community-based services specifically intended for those receiving palliative and end-of-life care.

While we work to dismantle structural forces that promote housing precarity and state-sanctioned disablement, debility, and health disparity, we must also turn our attention to intervening in the present. Homeless services and their research partners have begun to identify and address the needs of aging populations within the housing care continuum, but without careful consideration of the various trajectories patients experience when seriously ill and homeless. Through concurrent exploration of the patterns of movement of palliative care patients facing homelessness, and development of cross-site and cross-disciplinary knowledge from on-the-ground professionals, the study has identified several opportunities for practice, programming, policy and research across interlocking health and housing systems. Potential solutions included interdisciplinary capacity-building, support for peer and neighbor mutual aid, environmental design changes, new housing innovations, expanded mobile healthcare, and reforms to coordinated entry. Listening to front-line experts can allow us to strategically advocate for necessary reforms and invest wisely in health and housing justice interventions.

Dorothy Day, co-founder of the Catholic Worker Movement, once wrote, “everybody talks about security, and everybody shudders at the idea of poverty. And in fear and anguish people succumb, mentally and physically, until our hospitals, especially our mental hospitals, are crowded all over the country… the universal crisis in the world today is because of love of money” (1952, p. 2). Precarity scholars postulate that precarity in the United States is a mechanism that keeps citizens dependent on the current economic and labor structures (Lorey, 2015). As Day suggests, the political refusal of notions of stability may be required. Goal-concordant patient care becomes more possible in an environment where those of us in healthcare institutions, universities, government service, and non-profit work engage in the refusal of the carceral logics that uphold the continued stratification of our cities. A different kind of care is possible; when researchers, policy makers, and practitioners commit to bringing knowledge, resources, curiosity, and an ethic of care to marginalized healthcare users, we become better equipped for designing, funding, and implementing programs to address a multitude of needs across many places and phases of care.

REFERENCES

A-Mark Foundation (02 Mar 2022). Tiny Home Villages: Construction and operating costs of Tiny Homes to decrease homelessness in Los Angeles. https://amarkfoundation.org/tiny-home-villages/?hilite=los+angeles+tiny+home

Adult Family Home Council (n.d.). The adult family home option: Our mission. https://adultfamilyhomecouncil.org/

Agathangelou, A. M., Bassichis, M. D., & Spira, T. L. (2008). Intimate investments: Homonormativity, global lockdown, and the seductions of empire. *Radical History Review*, *100*, 120-143. https://doi.org/10.1215/01636545-2007-025

Ahmadu, M., Herron, R. V., Allan, J. A., & Waddell, C. M. (2021). Identifying places that foster mental health and well-being among rural men. Health & Place, 71, 102673. https://doi.org/10.1080/13668250020019566-1

Ahmed, S. (2004). Affective Economies. *Social Text*, *22*(2), 117-139. https://doi.org/10.1215/01642472-22-2_79-117

Aiken, C., Reina, V. J., & Culhane, D. P. (2021). Understanding low-income Hispanic housing challenges and the use of housing and homelessness assistance. *Cityscape*, *23*(2), 123-158. https://doi.org/174.127.242.42

Aldridge, R. W., Story, A., Hwang, S. W., Nordentoft, M., Luchenski, S. A., Hartwell, G., & Hayward, A. C. (2018). Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: a systematic review and meta-analysis. *The Lancet*, *391*(10117), 241-250. https://doi.org/10.1016/S0140-6736(17)31869-X

Alexandrescu, L. (2017). NPS and the methadone queue: Spillages of space and time. International Journal of Drug Policy, 40, 50-586. https://doi.org/10.1016/J.DRUGPO.2016.09.009

All Home (2021). Seattle/King County point-in-time count of individuals experiencing homelessness. *King County Regional Homeless Authority*. Retrieved on 3 Dec 2021 from https://kcrha.org/king-county-point-in-time-count/

Allen, N., & Davey, M. (2018). The value of constructivist grounded theory for built environment researchers. *Journal of Planning Education and Research, 38*(2), 222-232. https://doi.org/10.1177/0739456X17695195

American Health Care Association (2021). Closed doors, open hearts: Nursing homes and COVID-19 [Film]. https://youtu.be/KtK_RIIyMpA

Amster, R. (2008). *Lost in space: The criminalization, globalization, and urban ecology of homelessness*. New York: LFB Scholarly Publishing.

Anderson, M.B., Hanson, E.C., Arms, Z., & Tsikalas, S.G. (2022). Class monopoly rent, property relations, and Portland's homeless crisis. *Urban Geography, 43*(2), 252-272. https://doi.org/10.1080/02723638.2020.1847937.

Annear, M., Keeling, S., Wilkinson, T. I. M., Cushman, G., Gidlow, B. O. B., & Hopkins, H. (2014). Environmental influences on healthy and active ageing: a systematic review. *Ageing and Society*, *34*(4), 590-622. https://doi.org/10.1017/S0144686X1200116X

Annison, J. E. (2000). Towards a clearer understanding of the meaning of" home". *Journal of Intellectual and Developmental Disability, 25*(4), 251-262. https://doi.org/10.1080/13668250020019566-1

Anzaldúa, G. (2012). *Borderlands/ La frontera: The new mestiza* (4th Ed.). San Francisco: Aunt Lute Books. ISBN: 0933216254.

Arnold, R. M., Back, A. L., Baile, W. F., Edwards, K. A., & Tulsky, J. A. (2017). The Oncotalk/Vital talk model. *Oxford Textbook of Communication in Oncology and Palliative Care*, 363. https://doi.org/10.1093/med/9780198736134.003.0056

Bailey, K. (1994). An introduction to classification techniques. In *Typologies and Taxonomies*. Los Angeles: SAGE Publications. ISBN: 9781412986397.

Balagot, C., Lemus, H., Hartrick, M., Kohler, T., & Lindsay, S.P. (2019). The homeless coordinated entry system: The VI-SPDAT and other predictors of establishing eligibility for services for single homeless adults. *Journal of Social Distress and the Homeless, 28*(2), 149-157. https://doi.org/10.1080/10530789.2019.1622858

Bancroft, K. H. (2012). Zones of exclusion: Urban spatial policies, social justice, and social services. *Journal of Sociology and Social Welfare*, *39*(3), 63-84. https://scholarworks.wmich.edu/jssw/vol39/iss3/5

Barnato A.E., Anthony D.L., Skinner J., Gallagher P.M., Fisher E.S. (2009). Racial and ethnic differences in preferences for end-of-life treatment. *Journal of General Internal Medicine, 24*(6), 695-701. https://doi.org/10.1007/s11606-009-0952-6

Batko, S., Oneto, A.D., & Shroyer, A. (December 2020). Unsheltered homelessness: Trends, characteristics, and homeless histories. *Urban Institute Metropolitan Housing and Communities Policy Center.* https://www.urban.org/sites/default/files/publication/103301/unsheltered-homelessness.pdf

Bazargan, M., & Bazargan-Hejazi, S. (2021). Disparities in palliative and hospice care and completion of advance care planning and directives among non-Hispanic blacks: A scoping review of recent literature. *American Journal of Hospice and Palliative Medicine*, *38*(6), 688-718. https://doi.org/10.1177/1049909120966585

Beckett, K. The uses and abuses of police discretion: Toward harm reduction policing. *Harvard Law & Policy Review, 10,* 77-100. Retrieved from https://harvardlpr.com/wp-content/uploads/sites/20/2016/02/10.1_6_Beckett.pdf

Bell, S. L., Foley, R., Houghton, F., Maddrell, A., & Williams, A. M. (2018). From therapeutic landscapes to healthy spaces, places, and practices: A scoping review. Social Science & Medicine, 196, 123-130. https://doi.org/10.1016/j.socscimed.2017.11.035

Belcher, J.R., Deforge, B.R., & Zanis, D.A. (2005). Why has the social work profession lost sight of how to end homelessness? *Journal of Progressive Human Services, 16*(2), 5-23. https://doi.org/10.1300/J059v16n02_02

Belgrave, L.L., Charmaz, K. (2014). Studying illness and dying through constructivist grounded theory. In van Brussel, L., Carpentier, N. (Eds). *The social construction of death*. London: Palgrave Macmillan. https://doi.org/10.1057/9781137391919_3

Ben-Moshe, L. (2020). *Decarcerating disability: Deinstitutionalization and prison abolition*. University of Minnesota Press. https://doi.org/10.5749/j.ctv10vm2vw

Ben-Moshe, L., Chapman, C., & Carey, A.C. (2014). *Disability incarcerated: Imprisonment and disability in the United States and Canada*. Palgrave Macmillan. https://doi.org/10.1057/9781137388476

Benfer, E.A., Vlahov, D., Long, M.Y., Walker-Wells, E., Pottenger Jr., J.L., Gonsalves, G., & Keene, D.E. (2021). *Journal of Urban Health, 98*(1), 1-12. https://doi.org/10.1007/s11524-020-00502-1

Berlant, L. (2007). Slow death. *Critical Inquiry,* 33(4). 754-780. https://doi.org/10.1086/521568

Bezgrebelna, M., McKenzie, K., Wells, S., Ravindran, A., Kral, M., Christensen, J., & Kidd, S. A. (2021). Climate change, weather, housing precarity, and homelessness: a systematic review of reviews. *International Journal of Environmental Research and Public Health*, *18*(11), 5812. https://doi.org/10.3390/ijerph18115812

Bignante, E. (2020). Homeless healers and the production of landscapes of healing and wellbeing on the Venice Beach boardwalk, Los Angeles. *Geoforum, 113*, 92-100. https://doi.org/10.1016/j.geoforum.2020.05.006

Bigonnesse, C., & Chaudhury, H. (2020). The landscape of "aging in place" in gerontology literature: Emergence, theoretical perspectives, and influencing factors. *Journal of Aging and Environment*, *34*(3), 233-251. https://doi.org/10.1080/02763893.2019.1638875

Blomley, N. (2007). How to turn a beggar into a bus stop: Law, traffic and the 'function of the place'. *Urban Studies, 44*(9), 1697-1712. https://doi.org/10.1080/00420980701427507

Boodman, E. (2019). Nursing home abolition: Prisons and the institutionalization of older adult care. *Journal of Ethical Urban Living, 2*(1), 1-21. http://jeul.cognethic.org/jeulv2i1.pdf#page=4

Boyd, J., Cunningham, D., Anderson, S., & Kerr, T. (2016). Supportive housing and surveillance. *International Journal of Drug Policy, 34,* 72-79. https://doi.org/10.1016/j.drugpo.2016.05.012

Branch, W.T., Torke, A., Brown-Haithco, R. C. (2006). The importance of spirituality in African-Americans' end-of-life experience. *J Gen Intern Med, 21*(11), 1203-1205. https://doi.org/10.1111/j.1525-1497.2006.00572.x

Brewer, R. M., & Heitzeg, N. A. (2008). The racialization of crime and punishment: Criminal justice, color-blind racism, and the political economy of the prison industrial complex. *American Behavioral Scientist*, *51*(5), 625-644. https://doi.org/10.1177/0002764207307745

Brewster, L. (2014). The public library as therapeutic landscape: A qualitative case study. *Health & Place*, (26), 94-99. https://doi.org/10.1016/j.healthplace.2013.12.015

Briggs, D., Telford, L., Lloyd, A., Ellis, A., & Kotzé, J. (2021). Locked Out: Migrant Workers, Refugees and Stateless Citizens and the Homeless. In Briggs, et al. (Eds). *Lockdown* (pp. 243-266). Palgrave Macmillan.

Brown, R. T., Thomas, M. L., Cutler, D. F., & Hinderlie, M. (2013). Meeting the housing and care needs of older homeless adults: A permanent supportive housing program targeting homeless elders. *Seniors Housing & Care Journal, 21*(1), 126–135. https://doi.org/PMC3980491

Brown, R.T., Hemati, K., Riley, E.D., Lee, C.T. Ponath, C., Tieu, L., Guzman, D., & Kushel, M.B. (2017). Geriatric conditions in a population-based sample of older homeless adults. *The Gerontologist, 57*(4), 757–766. https://doi.org/10.1093/geront/gnw011

Brown, R. T., Guzman, D., Kaplan, L. M., Ponath, C., Lee, C. T., & Kushel, M. B. (2019). Trajectories of functional impairment in homeless older adults: Results from the HOPE HOME study. *PloS One*, *14*(8), e0221020-e0221020 https://doi.org/10.1371/journal.pone.0221020

Bryant, A., & Charmaz, K. (2019). The SAGE handbook of current developments in grounded theory. London: SAGE Publications Ltd. https://doi.org/10.4135/9781526436061

Bruey, V. F. (2019). Development-induced displacement and homelessness in Seattle, Washington. *Artha - Journal of Social Sciences*, *18*(2), 1-25. https://doi.org/10.12724/ajss.49.1

Burch, S. (2021). C*ommitted: Remembering native kinship in and beyond institutions*. Chapel Hill: University of North Carolina Press. ISBN: 978-1-4696-6336-4

Bullock-Johnson, R., & Bullock, K. (2020). Exploring mental health treatment and prevention among homeless older adults. In Bacha, U. Rozman, U., Turk, S. (Eds.). Healthcare Access - Regional Overviews. Intech Open. https://doi.org/10.5772/intechopen.89731

Burgard, S. A., Seefeldt, K. S., & Zelner, S. (2012). Housing instability and health: findings from the Michigan Recession and Recovery Study. *Social Science & Medicine*, *75*(12), 2215-2224. https://doi.org/10.1016/j.socscimed.2012.08.020

Burge, F., Lawson, B., Johnston, G., Asada, Y., McIntyre, P. F., & Flowerdew, G. (2015). Preferred and actual location of death: What factors enable a preferred home death? *Journal of Palliative Medicine*, *18*(12), 154-1059. https://doi.org/10.1089/jpm.2015.0177

Burns, V.F., Sussman, T., & Bourgeois-Guerin, V. (2018). Later-life homelessness as disenfranchised grief. *Canadian Journal on Aging, 37*(2), 171-184. https://doi.org/10.1017/S0714980818000090

Burns, V. F. (2016). Oscillating in and out of place: Experiences of older adults residing in homeless shelters in Montreal, Quebec. *Journal of Aging Studies*, *39*, 11-20. https://doi.org/10.1016/j.jaging.2016.08.001

Byrne, T., Roncarati, J. S., & Miller, D. P. (2021). Predictors of nursing home admission among a cohort of homeless older adults entering emergency shelter. *Medical Care*, *59*, S212-S219. https://doi.org/10.1097/MLR.0000000000001500

Cai, Y. & Lalani, N. (2021). Examining barriers and facilitators to palliative care access in rural areas: A scoping review. *American Journal of Hospice and Palliative Medicine, 39*(1), 123-130. https://doi.org/10.1177/10499091211011145

Cambridge University (2013). Cambridge advanced learner's dictionary (4th Ed.). Cambridge: Cambridge University Press.

Canham, S. L., Moore, P., Custodio, K., & Bosma, H. (2021). Homeism: Naming the Stigmatization and Discrimination of Persons Experiencing Homelessness. *Housing, Theory and Society*, 1-17. https://doi.org/10.1080/14036096.2021.2014558

Canham, S.L., Walsh, C.A., Sussman, T., Humphries, J., Nixon, L., & Burns, V.F. (2021). Identifying shelter and housing models for older people experiencing homelessness. *Journal of Aging and Environment*, https://doi.org/10.1080/26892618.2021.1955806

Canham, S. L., Weldrick, R., Sussman, T., Walsh, C. A., & Mahmood, A. (2022). Aging in the right place: A conceptual framework of indicators for older persons experiencing homelessness. *The Gerontologist*. https://doi.org/10.1093/geront/gnac023

Cawley, C., Kanzaria, H.K., Zevin, B., Doran, K.M., Kushel, M., Raven, M.C. (2022). Mortality among people experiencing homelessness in San Francisco during the COVID-19 pandemic. *JAMA Network Open, 5*(3), e221870. https://doi.org/10.1001/jamanetworkopen.2022.1870

Chadwick, K. (2014). *Managing the minefield of residential treatment: Protecting against burnout and compassion fatigue*. [Doctoral dissertation, University of Oklahoma]. https://shareok.org/bitstream/handle/11244/10475/2014_Katie_Chadwick_Dissertation.pdf?sequence=2

Chang, B.H., Stein, N. R., Trevino, K., Stewart, M., Hendricks, A., & Skarf, L. M. (2012). End-of-life spiritual care at a VA medical center: Chaplains' perspectives. *Palliative & Supportive Care*, *10*(4), 273-278. https://doi.org/10.1017/S1478951511001003

Charmaz, K. (1999). Stories of suffering: Subjective tales and research narratives. *Qualitative Health Research, 9*(3), 362-382. https://doi.org/10.1177/104973299129121910

Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis*. London; Thousand Oaks, CA: Sage Publications. ISBN: 0761973524

Charmaz, K. (2014). *Constructing grounded theory* (2nd Ed.). London; Thousand Oaks, CA: SAGE Publications. ISBN: 9780761973539

Charmaz, K., & Thornberg, R. (2021). The pursuit of quality in grounded theory. *Qualitative Research in Psychology, 18*(3), 305-327. https://doi.org/10.1080/14780887.2020.1780357

Chen, A. Y., Chen, B., & Kuo, C. C. (2020). Better continuity of care improves the quality of end-of-life care among elderly patients with end-stage renal disease. *Scientific Reports*, *10*(1), 1-10. https://doi.org/10.1038/s41598-020-76707-w

Chin, M. H. (2021). Advancing health equity in patient safety: a reckoning, challenge, and opportunity. *BMJ Quality & Safety*, *30*(5), 356-361. http://dx.doi.org/10.1136/bmjqs-2020-011920

Chisholm, L., Zhang, N. J., Hyer, K., Pradhan, R., Unruh, L., & Lin, F.-C. (2018). Culture Change in Nursing Homes: What Is the Role of Nursing Home Resources? *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. https://doi.org/10.1177/0046958018787043

Chodos, A. H., Ahalt, C., Cenzer, I. S., Myers, J., Goldenson, J., & Williams, B. A. (2014). Older jail inmates and community acute care use. *American Journal of Public Health, 104*(9), 1728-1733. https://doi.org/10.2105/AJPH.2014.301952

Chow, K. & Dahlin, C. (2018). Integration of palliative care and oncology nursing. *Seminars in Oncology Nursing, 34*(3), 192-201. https://doi.org/10.1016/j.soncn.2018.06.001

Coalition to End Homelessness (2021). State of homelessness: 2021 edition. Retrieved on 3 Dec 2021 from https://endhomelessness.org/homelessness-in-america/homelessness-statistics/state-of-homelessness-2021/

Cole, W. (27 January 2022). Hawaii police deploys $150,000 robot dog Spot to take homeless people’s temperature in fight against Covid despite criticism it dehumanizes them. *Daily Mail*. Retrieved on 23 March 2022 from https://www.dailymail.co.uk/news/article-10448379/Cops-Honolulu-use-robot-dog-temperature-homeless-people.html

Cornes, M., Whiteford, M., Manthorpe, J., Neale, J., Byng, R., Hewett, N., & Tinelli, M. (2018). Improving hospital discharge arrangements for people who are homeless: A realist synthesis of the intermediate care literature. *Health & Social Care in the Community, 26(*3), e345-e359. https://doi.org/10.1111/hsc.12474

Corporation for Supportive Housing (2022). Supportive Housing 101: What is supportive housing? https://www.csh.org/supportive-housing-101/

Corporation for Supportive Housing (2016). Healthy aging in supportive housing: A toolkit for service providers, developers, and property managers. https://www.csh.org/resources/healthy-aging-in-supportive-housing-toolkit/

Couch, L. (2017). Section 202: Supportive Housing for the Elderly. *National Low Income Housing Coalition,* 4-28. https://www.nlihc.org/sites/default/files/AG-2018/Ch04-S07_Section-202_2018.pdf

Crane, M., Warnes, A. M., & Fu, R. (2006). Developing homelessness prevention practice: combining research evidence and professional knowledge. *Health & Social Care in the Community, 14*(2), 156-166. http://doi.org/10.1111/j.1365-2524.2006.00607.x

Cronley, C. (2020). Invisible intersectionality in measuring vulnerability among individuals experiencing homelessness–critically appraising the VI-SPDAT. *Journal of Social Distress and Homelessness*, 1-11. https://doi.org/10.1080/10530789.2020.1852502

Cross, S.H., Kaufman, B.G., Taylor, D.H., Kamal, A.H., & Warraich, H.J. (2019). Trends and factors associated with place of death for individuals with dementia in the United States. *Journal of American Geriatrics Society, 68,* 250-255. https://doi.org/10.1111/jgs.16200

Cross, S. H., Kaufman, B. G., Quest, T. E., & Warraich, H. J. (2021). National trends in hospice facility deaths in the United States, 2003–2017. *Journal of Pain and Symptom Management*, *61*(2), 350-357. https://doi.org/10.1016/j.jpainsymman.2020.08.026

Crystal, S., Shea, D. G., & Reyes, A. M. (2017). Cumulative advantage, cumulative disadvantage, and evolving patterns of late-life inequality. *The Gerontologist*, *57*(5), 910-920. https://doi.org/10.1093/geront/gnw056

Culhane, D. P., Metraux, S., Byrne, T., Stino, M., & Bainbridge, J. (2013). The age structure of contemporary homelessness: Evidence and implications for public policy. *Analyses of Social Issues and Public Policy*, *13*(1), 228-244. https://doi.org/10.1111/asap.12004

Culhane, D., Doran, K., Schretzman, M., Johns, E., Treglia, D., Byrne, T., Metraux, S., & Kuhn, R. (2019). The emerging crisis of aged homelessness in the U.S.: Could cost avoidance in health care fund housing solutions? *International Journal of Population Data Science*, *4*(3). https://doi.org/10.23889/ijpds.v4i3.1185

Curtis, S., Gesler, W., Priebe, S., Francis, S. (2009). New spaces of inpatient care for people with mental illness: A complex ‘rebirth’ of the clinic? *Health & Place,15*(1). https://doi.org/10.1016/j.healthplace.2008.06.007

Cutshaw, C. A., Woolhandler, S., Himmelstein, D. U., & Robertson, C. (2016). Medical causes and consequences of home foreclosures. *International Journal of Health Services*, *46*(1), 36-47. https://doi.org/10.1177/0020731415614249

Davis, S. (2004). *Designing for the homeless: Architecture that works*. University of California Press. ISBN: 0520235258

Davis-Berman, J. (2016). Serious illness and end-of-life care in the homeless: Examining a service system and a call for action for social work. *Social Work & Society*, *14*(1). ISSN: 1613-8953

Day, D. (May 1952). Poverty and precarity. *The Catholic Worker, 2*(6), p 1-4.

Dear, M. J., & Wolch, J.R. (2015). *Landscapes of Despair: From Deinstitutionalization to Homelessness* (2nd Eds). Princeton: Princeton University Press. ISBN: 9780691601403

Dedoose Version 9.0.46 (2021). web application for managing, analyzing, and presenting qualitative and mixed method research data. Los Angeles, CA: SocioCultural Research Consultants, LLC. www.dedoose.com.

DeMatteo, D., Shah, S., Murphy, M., & Koller, J. P. (2013). Treatment models for clients diverted or mandated into drug treatment. In B. S. McCrady & E. E. Epstein (Eds.), Addictions: A comprehensive guidebook (pp. 551–571). Oxford University Press. ISBN: 9780195114898

Denzin, N.K. and Lincoln, Y. (2013). *The Landscape of Qualitative Research* (4th Ed.). SAGE Publications, Thousand Oaks, California, CA. ISBN: 9781412957588

Depaola, S. J., Griffin, M., Young, J. R., & Neimeyer, R. A. (2003). Death anxiety and attitudes toward the elderly among older adults: The role of gender and ethnicity. *Death Studies*, *27*(4), 335-354. ISSN: 0748-1187

DeVerteuil, G. (2015). Conceptualizing violence for health and medical geography. *Social Science & Medicine (1982)*, *133*, 216-222. https://doi.org/10.1016/j.socscimed.2015.01.018

Devlin A.S., Andrade C.C. (2017) Quality of the hospital experience: Impact of the physical environment. In: Fleury-Bahi G., Pol E., Navarro O. (Eds) *Handbook of Environmental Psychology and Quality of Life Research*. Springer https://doi.org/10.1007/978-3-319-31416-7_23

Dolmage, J. (2018). *Academic ableism: Disability and higher education*. Baltimore, Maryland: Project Muse. ISBN: 9780472073719

Dormehl, L. (7 Dec 2020). Meet Ghost Robotics, the Boston Dynamics of combat bots. *Digital Trends*. Retrieved on March 23, 2022, from https://www.digitaltrends.com/features/ghost-robotics-military-bots/

Dragojlovic, A. Affective geographies: Intergenerational hauntings, bodily affectivity, and multiracial subjectivities. *Subjectivity, 8,* 315–334 (2015). https://doi.org/10.1057/sub.2015.15

Duan, Y., Mueller, C.A., Yu, F., & Talley, K.M. (2020). The effects of nursing home culture change on resident quality of life in U.S. nursing homes: An integrative review. *Research in Gerontological Nursing, 13*(4), 210-224. https://doi.org/10.3928/19404921-20200115-02

Duckles, J.M., Moses, G., & Moses, R. (2019). Community-based Participatory Research and Constructivist Grounded Theory: Aligning Transformative Research with Local Ways of Being and Knowing. (2019). In Bryant & Charmaz (Eds). SAGE handbook of current developments in grounded theory. London; Thousand Oaks, CA: SAGE Publications. https://doi.org/10.4135/9781526436061.n33

Eales, L., & Peers, D. (2021). Care haunts, hurts, heals: The promiscuous poetics of queer crip Mad care. *Journal of Lesbian Studies*, *25*(3), 163-181. https://doi.org/10.1080/10894160.2020.1778849

Ecker, J., Aubry, T., & Sylvestre, J. (2019). A review of the literature on LGBTQ adults who experience homelessness. *Journal of Homosexuality*, *66*(3), 297-323. https://doi.org/10.1080/00918369.2017.1413277

Eisenberg, A. (2017). "A shelter can tip the scales sometimes": Disinvestment, gentrification, and the neighborhood politics of homelessness in 1980s New York City. *Journal of Urban History*, *43*(6), 915-931. https://doi.org/10.1177/0096144217714762

Elbaum, A. (2020). Black lives in a pandemic: implications of systemic injustice for end-of-life care. *Hastings Center Report, 50*(3), 58-60. https://doi.org/10.1002/hast.1135

Ellis, B., Melady, D., Foster, N., Sinha, S., Lau, V., Saraga, S., & McLeod, S. L. (2020). Using volunteers to improve the experience of older patients in the emergency department. *Canadian Journal of Emergency Medicine*, *22*(4), 514-518. https://doi.org/10.1017/cem.2020.9

Estrada, L. V., Agarwal, M., & Stone, P. W. (2021). Racial/ethnic disparities in nursing home end-of-life care: A systematic review. *Journal of the American Medical Directors Association*, *22*(2), 279-290. https://doi.org/10.1016/j.jamda.2020.12.005

Etkind, S. N., Bone, A. E., Lovell, N., Cripps, R. L., Harding, R., Higginson, I. J., & Sleeman, K. E. (2020). The role and response of palliative care and hospice services in epidemics and pandemics: A rapid review to inform practice during the COVID-19 Pandemic. *Journal of Pain and Symptom Management*, *60*(1), e31-e40. https://doi.org/10.1016/j.jpainsymman.2020.03.029

Evans, J., Semogas, D., Smalley, J.G., & Lohfield, L. (2015) "This place has given me a reason to care": Understanding managed alcohol programs as enabling places in Canada. *Health & Place (33)*, 118–24. https://doi.org/10.1016/J.HEALTHPLACE.2010.09.012

Evans, J., & Baker, T. (2021). Breaking through the epistemic impasse: Ending homelessness with the invention of 'functional zero' in the Anglo-American world. *Futures*, *129*, 102730. https://doi.org/10.1016/j.futures.2021.102730

Fazel, S., Geddes, J. R., & Kushel, M. (2014). The health of homeless people in high-income countries: Descriptive epidemiology, health consequences, and clinical and policy recommendations. *The Lancet*, *384*(9953), 1529-1540. https://doi.org/10.1016/S0140-6736(14)61132-6

Fine, M., Torre, M. E., Frost, D., Cabana, A., & Avory, S. (2018). Refusing to check the box. In Gallagher, K. (Eds). *The methodological dilemma revisited: Creative, critical, and collaborative approaches to qualitative research for a new era*. New York: Routledge. ISBN 978-1-138-55511-2

Fine, P.G. (2018). Hospice underutilization in the U.S.: The misalignment of regulatory policy and clinical reality. *Journal of Pain and Symptom Management, 56*(5), 808-815. https://doi.org/10.1016/j.jpainsymman.2018.08.005

Finlay, J., Franke, T., McKay, H., & Sims-Gould, J. (2015). Therapeutic landscapes and wellbeing in later life: Impacts of blue and green spaces for older adults. *Health & Place, 34*, 97-106. https://doi.org/10.1016/j.healthplace.2015.05.001

Finlay, J. M. (2018). *Cities of (in)difference: A mixed-methods analysis of place and wellbeing in later life*. [Doctoral dissertation, University of Michigan]. ProQuest Dissertation and Theses Global.

Ford, J., & Gomez-Lanier, L. (2017). Are tiny homes here to stay? A review of literature on the tiny house movement. Family and Consumer Sciences Research Journal, 45(4), 394-405. https://doi.org/10.1111/fcsr.12205

Fornili, K. S. (2018). Racialized mass incarceration and the War on Drugs: A critical race theory appraisal. *Journal of Addictions Nursing*, *29*(1), 65-72. https://doi.org/10.1097/JAN.0000000000000215

Foster, K. (2010). 'You'd think this roller coaster was never going to stop': Experiences of adult children of parents with serious mental illness. *Journal of Clinical Nursing*, *19*(21-22), 3143-3151. https://doi.org/10.1111/j.1365-2702.2010.03293.x

Foti, M. E. (2003). " Do It Your Way": A demonstration project on end-of-life care for persons with serious mental illness. Journal of Palliative Medicine, 6(4), 661-669. https://doi.org/10.1089/109662103768253830

Fraser, B., Pierse, N., Chisholm, E., & Cook, H. (2019). LGBTIQ+ homelessness: A review of the literature. *International Journal of Environmental Research and Public Health*, *16*(15), 2677. https://doi.org/10.3390/ijerph16152677

Frochen, S., & Pynoos, J. (2017). Housing for the elderly: Addressing gaps in knowledge through the lens of age-friendly communities. *Journal of Housing for the Elderly*, *31*(2), 160-177. https://doi.org/10.1080/02763893.2017.1309936

Furlotte, C., & Schwartz, K. (2017). Mental health experiences of older adults living with HIV: Uncertainty, stigma, and approaches to resilience. *Canadian Journal on Aging*, *36*(2), 125-140. https://doi.org/10.1017/S0714980817000022

Gardner, P.J. (2011). Natural neighborhood networks—Important social networks in the lives of older adults. *Journal of Aging Studies, 25*(3), 263-271. https://doi.org/10.1016/j.jaging.2011.03.007

Gediman, H. K. (1983). Annihilation anxiety: The experience of deficit in neurotic compromise formation. *International Journal of Psychoanalysis*, *64*(1), 59-70.

Gelman, M. (2020). Mismanaged care: Exploring the costs and benefits of private vs. public healthcare in correctional facilities. *NYU Law Review, 95* (5), 1386-1434. https://www.nyulawreview.org/issues/volume-95-number-5/mismanaged-care-exploring-the-costs-and-benefits-of-private-vs-public-healthcare-in-correctional-facilities/

Gesler, W. M. (1993). Therapeutic landscapes: theory and a case study of Epidaurus, Greece. *Environment and Planning D: Society and Space, 11*(2), 171-189. https://doi.org/10.1068/d110171

Giesbrecht, M., Stajduhar, K. I., Mollison, A., Pauly, B., Reimer-Kirkham, S., McNeil, R., & Rose, C. (2018). Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at end-of-life. *Health & Place, 53*, 43-51. https://doi.org/10.1016/j.healthplace.2018.06.005

Gilman, M., & Green, R. (2018). The surveillance gap: The harms of extreme privacy and data marginalization. *NYU Review of Law & Social Change*, *42*(2), 253.

Retrieved from https://socialchangenyu.com/review/the-surveillance-gap-the-harms-of-extreme-privacy-and-data-marginalization/

Glenister, D. (2012). Creative spaces in palliative care facilities: Tradition, culture, and experience. *American Journal of Hospice and Palliative Medicine, 29*(2), 89–92. https://doi.org/10.1177/1049909111412581

Gonyea, J. G., & Melekis, K. (2017). Older homeless women's identity negotiation: agency, resistance, and the construction of a valued self. *The Sociological Review*, *65*(1), 67–82. https://doi.org/10.1111/1467-954X.12369

Gonyea, J.G. & Grenier, A. (2021). Precarity in later life: Understanding risk, vulnerability, and resilience. *Generations, 45*(2). https://generations.asaging.org/understanding-precarity-later-life

Gonzales, E., Shen, H.-W., Perry, T. E., & Wang, Y. (2019). Intersections of Home, Health, and Social Engagement in Old Age: Formal Volunteering as a Protective Factor to Health After Relocation. *Research on Aging*, *41*(1), 31–53. https://doi.org/10.1177/0164027518773125

Golant, S. M. (2015). *Aging in the right place*. Baltimore: Health Professions Press.

Gordon, A. (2008). *Ghostly matters: Haunting and the sociological imagination* (2nd Ed). Minneapolis: University of Minnesota Press. ISBN: 9780816665006

Gramelspacher, G.P. & Gunderman, R. (2018). Dying poor needn't mean dying poorly: Insights from a safety-net hospital palliative care program. In Moller, D.W. (Eds). Dying at the margins: Reflections on justice and healing for inner-city poor. Oxford University Press. ISBN: 9780199760145

Grande, S. (2018). Refusing the university. In Tuck, E. & Yang (Eds). *Toward what justice?: Describing diverse dreams of justice in education*. Routledge.

Grande, S. (2017). Aging, precarity, and the struggle for Indigenous elsewheres. *International Journal of Qualitative Studies in Education,* 31(3), 168-176. https://doi.org/10.1080/09518398.2017.1401145

Greenfield, E. A. (2018). Age-Friendly initiatives, social inequalities, and spatial justice. *Hastings Center Report*, *48*, S41-S45. https://doi.org/10.1002/hast.912

Greenhalgh, T. (2016). Cultural contexts of health: the use of narrative research in the health sector. World Health Organization. Regional Office for Europe. https://doi.org/10.1590/1807-57622017.0240

Grenier, A. P., Barken, R. P., & McGrath, C. P. (2016). Homelessness and aging: The contradictory ordering of 'house' and 'home'. *Journal of Aging Studies*, *39*, 73-80. https://doi.org/10.1016/j.jaging.2016.11.002

Grenier, A., Barken, R., Sussman, T., Rothwell, D., Bourgeois-Guérin, V., & Lavoie, J.-P. (2016). A literature review of homelessness and aging: Suggestions for a policy and practice-relevant research agenda. *Canadian Journal on Aging*, *35*(1), 28-41. https://doi.org/10.1017/S0714980815000616

Grenier, A., & Phillipson, C. (2018). Precarious aging: Insecurity and risk in late life. *Hastings Center Report*, *48*(S3), S15-S18. https://doi.org/10.1002/hast.907

Groth, P. E. (1994). *Living downtown: The history of residential hotels in the United States*. Univ of California Press. ISBN: 0520219546

Gruneir, A., Mor, V., Weitzen, S., Truchil, R., Teno, J., & Roy, J. (2007). Where people die: A multilevel approach to understanding influences on site of death in America. *Medical Care Research and Review*, *64*(4), 351-378. https://doi.org/10.1177/1077558707301810

Handley, M. A., Kushel, M., Weeks, J., Olsen, P., Castillo, J., & Knight, K. R. (2022). Ground-truthing the experiences of homeless older adults' recent stays with family and friends: A case study of participatory data analysis. *Journal of Health Care for the Poor and Underserved*, *33*(1), 268–285. https://doi.org/10.1353/hpu.2022.0020

Hanhardt, C.B. (2013). *Safe space: Gay neighborhood history and the politics of violence*. Durham: Duke University Press. ISBN: 9780822378860

Hao, J., Garfield, M., Purao, S. (2022). The determinants of length of homeless shelter stays: Evidence-based regression analyses. *International Journal of Public Health, 66*. https://doi.org/10.3389/ijph.2021.1604273

Harborview Medical Center (n.d.). Mission statement. Retrieved from https://www.uwmedicine.org/locations/harborview-medical-center

Harner, V. (2021). Trans intracommunity support & knowledge sharing in the United States & Canada: A scoping literature review. *Health & Social Care in the Community*, *29*(6), 1715-1728. https://doi.org/10.1111/hsc.13276

Harris-Kojetin, L., Sengupta, M., Park-Lee, E., Valverde, R., Caffrey, C., Rome, V., & Lendon, J. (2016). Long-term care providers and services users in the United States: Data from the national study of long-term care providers, 2013-2014. *Vital and Health Statistics: Analytical and Epidemiological Studies* (38), 1-105. ISSN: 0886-4691

Health Communication Research Institute. (2019). History of Joshua's House. Retrieved on 29 May 2022 from https://joshuashousehospice.org/about/history/

Healthcare for the Homeless Clinicians Network. 2018. Adapting your practice: Recommendations for End-of-Life Care for People Experiencing Homelessness.

Retrieved November 14, 2021 from https://nhchc.org/wp-content/uploads/2019/08/2018-end-of-life-care-guidelines.pdf

Heben, A. (2014). Tent city urbanism: From self-organized camps to Tiny House Villages. Village Collaborative. ISBN: 0692248056

Hector, J., & Khey, D. (2018). The front line: EMS, law enforcement, and probation and parole. In Hector & Khey (Eds). Criminal Justice and Mental Health (pp. 47-73). Springer International Publishing. https://doi.org/10.1007/978-3-319-76442-9

Hefner, J.L., Hogan, T.H., Opoku-Agyeman, W., & Menachemi, N. (2021). Defining safety net hospitals in the health services research literature: a systematic review and critical appraisal. *BMC Health Serv Research, 21*, 278. https://doi.org/10.1186/s12913-021-06292-9

Heller, R., Gresko, R., & James, M. C. (2021). Aging in supportive housing: A case study. *Journal of Health Care for the Poor and Underserved, 32*(2), 615-621. https://doi.org/10.1353/hpu.2021.0090.

Henwood, B. F., Stanhope, V., Brawer, R., Weinstein, L. C., Lawson, J., Stwords, E., & Crossan, C. (2013). Addressing chronic disease within supportive housing programs. *Progress in Community Health Partnerships: Research, Education, and Action, 7*(1), 67–75. https://doi.org/10.1353/cpr.2013.0005

Herbert, S. K., & Beckett, K. (2010). *Banished: The new social control in urban America*. Oxford; New York: Oxford University Press. https://doi.org/10.1093/acprof:oso/9780195395174.001.0001

Herring, C. (2014). The new logics of homeless seclusion: Homeless encampments in America's West Coast cities. *City & Community*, *13*(4), 285-309. https://doi.org/10.1111/cico.12086

Hicks, K., Downey, L., Engelberg, R.A., Fausto, J.A., Starks, H., Dunlap, B., Sibley, J., Lober, W., Khandelwal, N., Loggers, E.T., and Randall, J. (2018). Predictors of death in the hospital for patients with chronic serious illness. Journal of Palliative Medicine, *21*(3), 307-314. http://doi.org/10.1089/jpm.2017.0127

Hinchliffe, S., Allen, J., Lavau, S., Bingham, N., & Carter, S. (2012) Biosecurity and the topologies of infected life: From borderlines to borderlands. *Transactions: Institute for British Geographies*. https://www.doi.org/10.1111/j.1475-5661.2012.00538.x

Holl, M., van den Dries, L., Wolf, J.R. (2016). Interventions to prevent tenant evictions: A systematic review. *Health and Social Care in the Community, 24*(5), 532-546. https://doi.org/10.1111/hsc.12257

hooks, b. (1989). *Talking back: Thinking feminist, thinking Black*. New York: Routledge. ISBN: 0896083527

Hopper, K., Shinn, M., Laska, E., Meisner, M., & Wanderling, J. (2008). Estimating numbers of unsheltered homeless people through plant-capture and post-count survey methods. *American Journal of Public Health*, *98*(8), 1438-1442. https://doi.org/10.2105/AJPH.2005.083600

Horwitz, L.I., Chang, C., Arcilla, H.N., Knickman, J.R. (2020). Quantifying health systems' investment in social determinants of health, by sector, 2017-2019. *Health Affairs, 39*(2). https://doi.org/10.1377/hlthaff.2019.01246

Hospice Foundation of America (n.d.). Signs of approaching death. Retrieved on 10 Apr 2022 from https://hospicefoundation.org/Hospice-Care/Signs-of-Approaching-Death

Hoyez, A. (2007). The ‘world of yoga’: The production and reproduction of therapeutic landscapes. *Social Science & Medicine, 65*(1), 112-124. https://doi.org/10.1016/j.socscimed.2007.02.050

Hubbell, S. A. (2017). Advance care planning with individuals experiencing homelessness: Literature review and recommendations for public health practice. *Public Health Nursing, 34*(5), 472-478. https://doi.org/10.1111/phn.12333

Hudson, B. F., Flemming, K., Shulman, C., & Candy, B. (2016). Challenges to access and provision of palliative care for people who are homeless: a systematic review of qualitative research. *BMC Palliative Care, 15*(1), 1-18. https://doi.org/10.1186/s12904-016-0168-6

Huffman, K. F., & Upchurch, G. (2018). The health of older Americans: a primer on Medicare and a local perspective. *Journal of the American Geriatrics Society, 66*(1), 25-32. https://doi.org/10.1111/jgs.15227

Hui, D. M. D. M., Nooruddin, Z. M. D., Didwaniya, N. M. D., Dev, R. M. D., De La Cruz, M. M. D., Kim, S. H. M. D., & Bruera, E. M. D. (2014). Concepts and definitions for “actively dying,” “end of life,” “terminally ill,” “terminal care,” and “transition of care”: A systematic review. *Journal of Pain and Symptom Management*, *47*(1), 77-89. https://doi.org/10.1016/j.jpainsymman.2013.02.021

Human Resources & Services Administration (2018). Bureau of Primary Health Care program terms and definitions. https://www.hrsa.gov/sites/default/files/grants/apply/assistance/Buckets/definitions.pdf

Human Resources Services Administration (16 Aug 2022). Uniform data system: 2021 health center reporting requirements. Retrieved from https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/pdf/2021-uds-manual.pdf#page=42

Hutchinson, R. N., Han, P. K. J., Lucas, F. L., Black, A., Sawyer, D., & Fairfield, K. (2021). Rural disparities in end-of-life care for patients with heart failure: Are they due to geography or socioeconomic disparity? *The Journal of Rural Health*. https://doi.org/10.1111/jrh.12597

Humphries, J., & Canham, S. L. (2021). Conceptualizing the shelter and housing needs and solutions of homeless older adults. *Housing Studies*, *36*(2), 157-179. https://doi.org/10.1080/02673037.2019.1687854

Hutson, S. P. (2016). Climbing back up the mountain: reflections from an exploration of end-of-life needs of persons living with HIV/AIDS in Appalachian Tennessee. *American Journal of Hospice and Palliative Medicine, 33*(10), 972-976. https://doi.org/10.1177/1049909115600857

IBM Corp (2020) IBM SPSS Statistics for Windows, Version 27.0. Armonk, NY: IBM Corp.

Ingold, T. (2000). *The perception of the environment: Essays on livelihood, dwelling and skill.* London, UK and New York, NY: Routledge. https://doi.org/10.4324/9780203466025

International Association for Hospice and Palliative Care (2022). Palliative care definition. Retrieved on 12 Apr 2022 from https://hospicecare.com/what-we-do/projects/consensus-based-definition-of-palliative-care/definition/

Isoke, Z. (2013). (Re)imagining home: Black women and the cultural production of Blackness in Newark. In: *Urban black women and the politics of resistance (The* *politics of intersectionality).* Palgrave Macmillan, New York. https://doi.org/10.1057/9781137045386_4

Jackson, A., Callea, B., Stampar, N., Sanders, A., De Los Rios, A., & Pierce, J. (2020). Exploring tiny homes as an affordable housing strategy to ameliorate homelessness: A Case Study of the Dwellings in Tallahassee, FL. *International Journal of Environmental Research and Public Health, 17*(2), 661. http://doi.org/10.3390/ijerph17020661

James, R., Flemming, K., Hodson, M., & Oxley, T. (2021). Palliative care for homeless and vulnerably housed people: scoping review and thematic synthesis. *BMJ Supportive & Palliative Care.* https://doi.org/10.1136/bmjspcare-2021-003020

James, S. E., Herman, J. L., Rankin, S., Keisling, M., Mottet, L., & Anafi, M. (2016). The 40 report of the 2015 U.S. transgender survey. Washington, DC: National Center for Transgender Equality. Retrieved on 15 Apr 2022 from https://transequality.org/sites/default/files/docs/usts/USTS-Full-Report-Dec17.pdf

Johannessen, A., Tevik, K., Engedal, K., & Helvik, A. S. (2021). Health professionals' experience of nursing home residents' consumption of alcohol and use of psychotropic drugs. *Nordic Studies on Alcohol and Drugs, 38*(2), 161-174. https://doi.org/10.1177/1455072520961890

Johnsen, S., Cloke, P. & May, J. (2005). Day centres for homeless people: Spaces of care or fear? *Social & Cultural Geography* 6(6), 787–811. https://doi.org/10.1080/14649360500353004

Johnson, I. M. (2022). Aging in the downtown corridor: Mapping the neighborhood experiences of Seattle's unhoused adults over age 50. *Journal of Aging Studies*, *60*, 100997. https://doi.org/10.1016/j.jaging.2021.100997

Johnson, M., & McRuer, R. (2014). Cripistemologies: Introduction. *Journal of Literary & Cultural Disability Studies*, *8*(2), 127-148. https://doi.org/10.3828/jlcds.2014.12

Jones, D. (2019). Review of navigation team 2018 quarter 2 report. *Seattle Office of City Auditor*. Retrieved on 27 Feb 2022 from https://www.seattle.gov/documents/Departments/CityAuditor/auditreports/Navigation%20Team%20Audit_2-7-2019_revised.pdf

Jones, M., & Alony, I. (2011). Guiding the use of grounded theory in doctoral studies – An example from the Australian film industry. International Journal of Doctoral Studies, *6*, 95-114. https://doi.org/10.28945/1429

Joy, M. (2018). Problematizing the age-friendly cities and communities program in Toronto. *Journal of Aging Studies, 47*, 49-56 https://doi.org/10.1016/j.jaging.2018.10.005

Källquist, A., & Salzmann-Erikson, M. (2019). Experiences of having a parent with serious mental illness: An interpretive meta-synthesis of qualitative literature. *Journal of Child and Family Studies*, *28*(8), 2056-2068. https://doi.org/10.1007/s10826-019-01438-0

Kang-Brown, J., Montagnet, C., & Heiss, J. (June 2021). People in jail and prison in spring 2021. *Vera Institute of Justice*. Retrieved on 14 Apr 2022 from https://www.vera.org/downloads/publications/people-in-jail-and-prison-in-spring-2021.pdf

Kaplan, L. M., Sudore, R. L., Arellano Cuervo, I., Bainto, D., Olsen, P., & Kushel, M. (2020). Barriers and solutions to advance care planning among homeless-experienced older adults. *Journal of Palliative Medicine, 23*(10), 1300-1306. https://doi.org/10.1089/jpm.2019.0550

Kassam, A., Skiadaresis, J., Alexander, S., & Wolfe, J. (2014). Parent and clinician preferences for location of end-of-life care: home, hospital, or freestanding hospice? *Pediatric Blood & Cancer*, *61*(5), 859-864. https://doi.org/10.1002/pbc.24872

Kaye, K. (2020). *Enforcing freedom: Drug courts, therapeutic communities, and the intimacies of the state*. Columbia University Press. ISBN 9780231172899

Kearns, R. A., & Collins, D. C. (2000). New Zealand children's health camps: Therapeutic landscapes meet the contract state. *Social Science & Medicine*, *51*(7), 1047-1059. https://doi.org/10.1016/S0277-9536(00)00020-4

Kearns, R. & Milligan, C. (2020). Placing therapeutic landscape as theoretical development in Health & Place. *Health & Place, 61*, 102224. https://doi.org/10.1016/J.HEALTHPLACE.2019.102224

Kearns, R., & Moon, G. (2002). From medical to health geography: Novelty, place, and theory after a decade of change. *Progress in Human Geography, 26*(5), 605-625. https://doi.org/10.1191/0309132502ph389oa

Kelley, R. D. G. (2018). Black study, Black struggle. *Ufahamu*, *40*(2). https://doi.org/10.5070/F7402040947

Kidd, S. A., Greco, S., & McKenzie, K. (2021). Global climate implications for homelessness: A scoping review. *Journal of Urban Health*, *98*(3), 385-393. https://doi.org/10.1007/s11524-020-00483-1

Kim H. Y. (2017). Statistical notes for clinical researchers: Chi-squared test and Fisher's exact test. *Restorative Dentistry & Endodontics*, *42*(2), 152–155. https://doi.org/10.5395/rde.2017.42.2.152

King County Medical Examiner's Office (2022). Homeless deaths investigated by the King County Medical Examiner's Office. Retrieved on 16 Apr 2022 from https://kingcounty.gov/depts/health/examiner/services/reports-data/homeless.aspx

Klingle, E. (2017). Junkyard for human junk: The unnatural ecology of urban poverty. In *Emerald City* (pp. 180–202). Yale University Press. https://doi.org/10.12987/9780300150124-010

Klop, H. T., De Veer, A. J., Van Dongen, S. I., Francke, A. L., Rietjens, J. A., & Onwuteaka-Philipsen, B. D. (2018). Palliative care for homeless people: a systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BMC Palliative Care*, *17*(1), 1-16. https://doi.org/10.1016/j.jpainsymman.2018.05.026

Ko E, Kwak J, Nelson-Becker H. (2015). What constitutes a good and bad death?: Perspectives of homeless older adults. *Death Studies, 39,* 422–32. https://doi.org/10.1080/07481187.2014.958629

Ko, E., & Nelson-Becker, H. (2014). Does end-of-life decision-making matter? Perspectives of older homeless adults. *American Journal of Hospice & Palliative Medicine*, *31*(2), 183-188. https://doi.org/10.1177/1049909113482176

Kogan, A. C., Wilber, K., & Mosqueda, L. (2016). Person-centered care for older adults with chronic conditions and functional impairment: A systematic literature review. *Journal of the American Geriatrics Society*, *64*(1), e1-e7. https://doi.org/10.1111/jgs.13873

Kohut, H. (1977). *The restoration of the self*. New York: International Universities Press. ISBN: 0823658104

Korman, H. (2007) Clash of the integrationists: The mismatch of civil rights imperatives in supportive housing for people with disabilities. Saint Louis University Public Law Review, (26)1, 3-43. https://scholarship.law.slu.edu/plr/vol26/iss1/4

Kortes-Miller, K., Boulé, J., Wilson, K., & Stinchcombe, A. (2018). Dying in long-term care: Perspectives from sexual and gender minority older adults about their fears and hopes for end of life. *Journal of Social Work in End-of-Life & Palliative Care*, *14*(2-3), 209-224. https://doi.org/10.1080/15524256.2018.1487364

Koss, C., & Ekerdt, D. J. (2017). Residential reasoning and the tug of the Fourth Age. *The Gerontologist*, *57*(5), 921-929. https://doi.org/10.1093/geront/gnw010

Krishnan, S. (28 Sep 2009). Decades of decay haunt infamous Aurora. *Seattle Times*. Retrieved on 1 Apr 2022. https://www.seattletimes.com/seattle-news/decades-of-decay-haunt-infamous-aurora/

Kuhn, R., & Culhane, D. P. (1998). Applying cluster analysis to test a typology of homelessness by pattern of shelter utilization: Results from the analysis of administrative data. *American Journal of Community Psychology, 26*(2), 207-232. https://doi.org/10.1023/A:1022176402357

Kushel, M. (2018). Homelessness: A potent risk factor for readmission. *Medical Care, 56*(6), p 457-459. https://doi.org/10.1097/mlr.0000000000000920

Kusmaul, N. & Anderson, K. (2018) Applying a trauma-informed perspective to loss and change in the lives of older adults. *Social Work in Health Care, 57*(5), 355-375. https://doi.org/10.1080/00981389.2018.1447531

Lamble, S. (2013). Queer necropolitics and the expanding carceral state: Interrogating sexual investments in punishment. *Law and Critique*, *24*(3), 229-253.https://doi.org/10.1007/s10978-013-9125-1

Lawrence-Lightfoot, S. (2005). Reflections on portraiture: A dialogue between art and science. *Qualitative Inquiry*, *11*(1), 3-15. https://doi.org/10.1177/1077800404270955

Lee, S., Wong, Y.I, & Rothbard, A.B. (2009). Factors associated with departure from supported independent living programs for persons with serious mental illness. *Psychiatric Services, 60*(3), 367-373. https://doi.org/10.1176/ps.2009.60.3.367

Leicht, K. T., & Fitzgerald, S. T. (2014). The real reason 60 is the new 30: Consumer debt and income insecurity in late middle age. *Sociological Quarterly*, *55*(2), 236-260. https://doi.org/10.1111/tsq.12054

Leung AK, Nayyar D, Sachdeva M, et al. (2015). Chronically homeless persons participation in an advance directive intervention: A cohort study. *Palliative Medicine, 29*, 746–55. https://doi.org/10.1177/0269216315575679

Levin, B. (December 2020). 20 years of hate: National Coalition for the Homeless hate crimes report 2018-2019. *National Coalition for the Homeless.* https://nationalhomeless.org/wp-content/uploads/2020/12/hate-crimes-2018-2019_web.pdf

Lewinson, T. (2014). Building a university-community partnership to explore health challenges among residents at extended-stay hotels. *Metropolitan Universities, 25*(2), 89-106. ISSN: 1047-8485

Lewinson, T., Thomas, M. L., & White, S. (2014). Traumatic transitions: Homeless women's narratives of abuse, loss, and fear. *Affilia, 29*(2), 192-205. https://doi.org/10.1177/0886109913516449

Leyva, B., Taber, J. M., & Trivedi, A. N. (2020). Medical Care Avoidance Among Older Adults. *Journal of Applied Gerontology*, *39*(1), 74-85. https://doi.org/10.1177/0733464817747415

Lichtenstein, B. (2017). Debt, death, and divorce: Aging into foreclosure in the US Deep South. *Housing and Society*, *44*(3), 173-189. https://doi.org/10.1080/08882746.2017.1378051

Li, J. F., & Lin, Z. X. (2016). Social benefit expenditures and stagflation: Evidence from the United States. *Applied Economics*, *48*(55), 5340-5347. https://doi.org/10.1080/00036846.2016.1176118

Lloyd, J., Patterson, T., & Muers, J. (2014). The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia, 15*(6), 1534-1561. https://doi.org/10.1177%2F1471301214564792

Lopez, A. M. (2020). Necropolitics in the "compassionate" city: Care/brutality in San Francisco. *Medical Anthropology*, *39*(8), 751-764. https://doi.org/10.1080/01459740.2020.1753046

Lorey, I. (2015). *State of insecurity: Government of the precarious*. London: Verso Books. ISBN: 1781687145, 9781781687147

Loukaitou-Sideris, A., & Ehrenfeucht, R. (2009). *Sidewalks: Conflict and negotiation over public space*. MIT Press.

Love, M., Wilton, R., DeVerteuil, G. (2012). 'You have to make a new way of life': women's drug treatment programmes as therapeutic landscapes in Canada. *Gender, Place & Culture, 19*(3), 382-396. https://doi.org/10.1080/0966369X.2011.609985

Luoni, S. (2019). Permitting a homeless transition village: Transactions between the informal and the formal. *The Plan*, *4*(1), 137-157. https://doi.org/10.15274/tpj.2019.04.01.9

Lyon-Callo, V. (2008). *Inequality, poverty, and neoliberal governance: Activist ethnography in the homeless sheltering industry*. University of Toronto Press. ISBN: 1551116030

Magaña López, M., Bevans, M., Wehrlen, L., Yang, L., & Wallen, G.R. (2017). Discrepancies in race and ethnicity documentation: A potential barrier in identifying racial and ethnic disparities. *Journal of Racial and Ethnic Health Disparities, 4*, 812-818. https://doi.org/10.1007/s40615-016-0283-3

Mallett, S. (2004). Understanding home: a critical review of the literature. *Sociological Review, 52*(1), 62-89. https://doi.org/10.1111/j.1467-954X.2004.00442.x

Manalansan, M. F. (2005). Race, violence, and neoliberal spatial politics in the global city. *Social Text*, *23*(3-4), 141-155. https://doi.org/10.1215/01642472-23-3-4_84-85-141

Manuel, J. I., Yuan, Y., Herman, D. B., Svikis, D. S., Nichols, O., Palmer, E., & Deren, S. (2017). Barriers and facilitators to successful transition from long-term residential substance abuse treatment. *Journal of Substance Abuse Treatment, 74,* 16-22. https://doi.org/10.1016/j.jsat.2016.12.001

Marcus, C., & Sachs, N. (2014). *Therapeutic landscapes: An evidence-based approach to designing healing gardens and restorative outdoor spaces*. Hoboken, NJ: John Wiley & Sons. ISBN: 1-118-42110-8

Marks, N. (2021). When the wheels come off: Actor-network therapy for mental health recovery in the bicycle repair workshop. *Sociology of Health & Illness, 43*(7), 1700-1719. https://doi-org.offcampus.lib.washington.edu/10.1111/1467-9566.13357

Marques, B., McIntosh, J., & Kershaw, C. (2019). Healing spaces: Improving health and well-being for the elderly through therapeutic landscape design. *International Journal of Arts and Humanities, 3*(2), 20-34. ISSN: 2581-3102

Marr, M. D., DeVerteuil, G., & Snow, D. (2009). Towards a contextual approach to the place–homeless survival nexus: An exploratory case study of Los Angeles County. *Cities, 26*(6), 307-317. https://doi.org/10.1016/j.cities.2009.07.008

Masters, R.K., Aron, L.Y., & Woolf, S.H. (2022). Changes in life expectancy between 2019 and 2021: United States and 19 peer countries. *BMJ Public & Global Health*. https://doi.org/10.1101/2022.04.05.22273393

Mayeda D.P., Ward K.T. (2019). Methods for overcoming barriers in palliative care for ethnic/racial minorities: a systematic review. *Palliative Support Care, 17*(6), 697-706. https://doi.org/10.1017/S1478951519000403

Mbembe, A. (2019). *Necropolitics*. Durham: Duke University Press. ISBN: 9781478006510.

McAllister, W., Lennon, M. C., & Kuang, L. (2011). Rethinking research on forming typologies of homelessness. *American Journal of Public Health, 101*(4), 596-601. https://doi.org/10.2105/AJPH.2010.300074

McCallum, K. J., Jackson, D., Walthall, H., & Aveyard, H. (2018). Exploring the quality of the dying and death experience in the emergency department: An integrative literature review. *International Journal of Nursing Studies*, *85*, 106-117. https://doi.org/10.1016/j.ijnurstu.2018.05.011

McCauley, H. L., Reid, T., & Sullivan, C. (Jul 2020). Assessing vulnerability, prioritizing risk: The limitations of the VI-SPDAT for survivors of domestic & sexual violence. *Safe Housing Partnerships National Resource Center on Domestic Violence*.

McFadden, E. S., & Lucio, J. (2014). Aging in (privatized) places: Subsidized housing policy and seniors. *Journal of Housing for the Elderly*, *28*(3), 268-287. https://doi.org/10.1080/02763893.2014.930364

McGranahan, C. (2016). Theorizing refusal: An Introduction. *Cultural Anthropology*, *31*(3), 319-325. https://doi.org/10.14506/ca31.3.01

McGuire, M., Bell, S. K., Wilson, M., & Llorente, M. D. (2021). Why persons with serious mental illness end up homeless. In Elspeth, C.R. & Llorente, M.D. (Eds). *Clinical Management of the Homeless Patient* (pp. 151-168). Springer. ISBN: 9783030701345.

McIntosh, J., Marques, B., and Hatton, W. (2018) Indigenous cultural knowledge for therapeutic landscape design. In Rosa, I.S., Lopes, J.C., Ribeiro, R., & Mende (Eds) *Handbook of research on methods and tools for assessing cultural landscape adaptation.* IGI Global: Hershey, PA.

McLeod, H., & Walsh, C. A. (2014). Shelter design and service delivery for women who become homeless after age 50. *Canadian Journal of Urban Research, 23*(1), 23-38.http://gale.com/apps/doc/A398951169/AONE?u=anon~2c8fa35b&sid=googleScholar&xid=dbf10368

McNeil, R., Guirguis-Younger, M., Dilley, L.B., Aubry, T.D., Turnbull, J. & Hwang, S.W. (2012). Harm reduction services as a point-of-entry to and source of end-of-life care and support for homeless and marginally housed persons who use alcohol and/or illicit drugs: A qualitative analysis. *BMC Public Health, 12*. https://doi.org/10.1186/1471-2458-12-312

McNeil, R., Guirguis-Younger, M. & Dilley, L.B. (2012) Recommendations for improving the end-of-life care system for homeless populations: A qualitative study of the views of Canadian health and social services professionals. *BMC Palliative Care, 11*(14). https://doi.org/10.1186/1472-684X-11-14

McSweeney-Feld, M. H., & Braunstein, N. (2020) The dilemma of nursing home closures: A case study of rural Maine nursing homes. *Maine Policy Review 29*(1), 9 -18. https://digitalcommons.library.umaine.edu/mpr/vol29/iss1/3

Medicaid (n.d.). Programs of all-inclusive care for the elderly benefits. Retrieved on 10 Apr 2021 https://www.medicaid.gov/medicaid/long-term-services-supports/pace/programs-all-inclusive-care-elderly-benefits/index.html

Medicare (n.d.) Hospice care. Retrieved on Apr 13, 2022 from https://www.medicare.gov/coverage/hospice-care .

Metzl, J. M., & Roberts, D. E. (2014). Structural competency meets structural racism: race, politics, and the structure of medical knowledge. *AMA Journal of*

Ethics, *16*(9), 674-690. https://doi.org/10.1001/virtualmentor.2014.16.9.spec1-1409

Meijering, L., Lettinga, A.T., Nanninga, C.S., Milligan, C. (2017). Interpreting therapeutic landscape experiences through rural stroke survivors' biographies of disruption and flow. J*ournal of Rural Studies 51*(1), 275-283. https://doi.org/10.1016/j.jrurstud.2016.06.004

Mickelson, K.D., & Kubzansky, L.D. (2003). Social distribution of social support: The mediating role of life events. *American Journal of Community Psychology,* 32(3/4). https://doi.org/10.1023/B:AJCP.0000004747.99099.7e

Millar, K. M. (2017). Toward a critical politics of precarity. *Sociology Compass*, *11*(6), 1-11. https://doi.org/10.1111/soc4.12483

Mills, J., Bonner, A., & Francis, K. (2006). The development of constructivist grounded theory. *International Journal of Qualitative Methods, 5*(1), 25-35. https://doi.org/10.1177/160940690600500103

Moczygema, L.R., Thurman, W., Tormey, K., Hudzik, A., Welton-Arndt, L., & Kim, E. (2021). GPS mobile health intervention among people experiencing homelessness: Pre-post study. *Journal of Medical Internet Research*, *9*(11), https://doi.org/10.2196/25553

Mokos, J. T. (2017). Stigmatized places as therapeutic landscapes: The beneficial dimensions of river-bottom homeless encampments. *Medicine Anthropology Theory, 4*, 123-150. https://doi.org/10.17157/mat.4.1.362

Molinsky, J. (17 Dec 2020). Ten insights about older households from the 2020 State of the Nation's Housing Report. *Joint Center for Housing Studies*. Retrieved on 16

Apr 2022 from https://www.jchs.harvard.edu/blog/ten-insights-about-older-households-2020-state-nations-housing-report

Montgomery, A.E., Cusack, M., Szymkowiak, D., Fargo, J., & O'Toole (2017). Factors contributing to eviction from permanent supportive housing: Lessons from HUD-VASH. *Evaluation and Program Planning*, *61*, 55-63. https://doi.org/10.1016/j.evalprogplan.2016.11.014

Montgomery, P., & Bailey, P. H. (2007). Field notes and theoretical memos in grounded theory. *Western Journal of Nursing Research, 29*(1), 65-79. https://doi.org/10.1177/0193945906292557

Moore, A., Carter, B., Hunt, A., Sheikh, K. (2013). 'I am closer to this place'—Space, place, and notions of home in lived experiences of hospice day care. *Health & Place, 19* (1), 151-158. https://doi.org/10.1016/j.healthplace.2012.11.002

Morgaine, K. (2015). Positionality and Privilege in Qualitative Research: Feminist Critical Praxis. In Wahab, S., Anderson-Nathe, B., & Gringeri, C. (Eds). *Feminisms in social work research*. (pp. 240-253). Routledge. https://doi.org/10.4324/9781315886992-24

Morgan, B.D. (2016). End-of-life care for patients with mental illness and personality disorders. In Coyle, Hospice and Palliative Nurses Association (Eds.) *Legal and ethical aspects of care*. Oxford University Press. ISBN: 9780190258061

Moxley, D. P., Washington, O. G., & Calligan, H. F. (2012). Narrative insight into risk, vulnerability, and resilience among older homeless African American women. *The Arts in Psychotherapy*, *39*(5), 471-478. https://doi.org/10.1016/j.aip.2012.08.002

Munday, D., Dale, J., & Murray, S. (2007). Choice and place of death: Individual preferences, uncertainty, and the availability of care. *Journal of the Royal Society of Medicine*, *100*(5), 211-215. https://doi.org/10.1177/014107680710000509

Narushima, M., & Kawabata, M. (2020). "Fiercely independent": Experiences of aging in the right place of older women living alone with physical limitations. *Journal of Aging Studies*, *54*, 100875-100875. https://doi.org/10.1016/j.jaging.2020.100875

National Academy for State Health Policy (May 2019). Palliative care: A primer for state policymakers. *National Academy for State Health Policy*. Retrieved 29 May 2022 from https://mainehospicecouncil.org/images/National_Academy_for_State_Health_Policy_NASHP_Palliative-Care_Primer_for_State_Policymakers.pdf

National Alliance to End Homelessness (2022). State of homelessness: 2021 edition. Retrieved on 30 Mar 2022 from https://endhomelessness.org/homelessness-in-america/homelessness-statistics/state-of-homelessness-2021/

National Healthcare for the Homeless Council (2021). Understanding homelessness: Where does homelessness happen? Retrieved on 3 Dec 2021 from https://nhchc.org/understanding-homelessness/

National Hospice and Palliative Care Organization (n.d.). CaringInfo: Getting prepared for care and being present. https://www.caringinfo.org/

National Institute on Aging (1 May 2017). Long term care: Residential facilities, assisted living, and nursing homes. https://www.nia.nih.gov/health/residential-facilities-assisted-living-and-nursing-homes

Nilsen, P. J. (2021). Homelessness in the aftermath of COVID-19. *Journal of Paramedic Practice: The Clinical Monthly for Emergency Care Professionals*, *13*(11), 456-459. https://doi.org/10.12968/jpar.2021.13.11.456

Noelke, C., & Beckfield, J. (2014). Recessions, job loss, and mortality among older U.S. adults. *American Journal of Public Health*, *104*(11), e126-e134. https://doi.org/10.2105/AJPH.2014.302210

O’Campo, P., Daoud, N., Hamilton-Wright, S., & Dunn, J. (2016). Conceptualizing housing instability: Experiences with material and psychological instability among women living with partner violence. *Housing Studies*, *31*(1), 1-19. https://doi.org/10.1080/02673037.2015.1021768

O’Carroll, A., Irving, N., O’Neill, J., & Flanagan, E. (2017). A review of a GP registrar-run mobile health clinic for homeless people. *Irish Journal of Medical Science, 186*(3), 541-546. https://doi.org/10.1007/s11845-016-1527-2

O'Carroll, A., & Wainwright, D. (2021). Doctor–patient interactions that exclude patients experiencing homelessness from health services: an ethnographic exploration. *BJGP Open, 5*(3). https://doi.org/10.3399/BJGPO.2021.0031

O’Connor, A. Carpenter, B. & Coughlan, B. (2018). An exploration of key issues in the debate between classic and constructivist grounded theory. *The Grounded Theory Review, 17*(1). ISSN: 1556-1550.

Ogden, L. P. (2014). “Waiting to go home”: Narratives of homelessness, housing, and home among older adults with schizophrenia. *Journal of Aging Studies*, *29*, 53-65. https://doi.org/10.1016/j.jaging.2014.01.002

Olivet, J., Wiley, C., Richard, M., Dones, M., Tripp, J., Beit-Arie, M., Yampolskaya, S., & Cannon, R. (2021). Racial inequity and homelessness: Findings from the SPARC study. *The Annals of the American Academic of Politic and Social Science, 693*(1), 82-100. https://doi.org/10.1177/00027162219910

Onwuegbuzie, A. J., Leech, N. L., & Collins, K. M. (2010). Innovative data collection strategies in qualitative research. *Qualitative Report, 15*(3), 696-726. https://doi.org/10.46743/2160-3715/2010.1171

OrgCode (Jan 25, 2022). A message from OrgCode on the VI-SPDAT moving forward. Retrieved from https://www.orgcode.com/blog/a-message-from-orgcode-on-the-vi-spdat-moving-forward

Orlovic, M., Smith, K., Mossialos, E. (2019). Racial and ethnic differences in end-of-life care in the United States: Evidence from the Health and Retirement Study (HRS). *SSM-Population Health, 7*, 100331. https://doi.org/10.1016/j.ssmph.2018.100331

Owens, K., & Green, C. (2020). Performing Millennial housing precarity: how (not) to live together. *Studies in Theatre and Performance*, *40*(1), 44-53. https://doi.org/10.1080/14682761.2019.1689738

Padgett, D.K., Henwood, B., Abrams, C., & Drake, R.E. (2008). Social relationships among persons who have experiences serious mental illness, substance abuse, and homelessness: Implications for recovery. *American Journal of Orthopsychiatry, 78*(3), 333-339. https://doi.org/10.1037/a0014155

Padymow, T., Turnbull, J., & Coyle, D. (2006). Shelter-based palliative care for the homeless terminally ill. *Palliative Medicine*, *20*(2), 81-86. https://doi.org/10.1191/0269216306pm11030a

Park, D.C., Radford, J.P, Vickers, M.H. (1998). Disability studies in human geography. *Progress in Human Geography, 22*(2), 208-233.

Parish, S. L., Grinstein-Weiss, M., & Hun Yeo, Y. (2010). Assets and income: Disability-based disparities in the United States. *Social Work Research*, *34*(2), 71-82. https://doi.org/10.1093/swr/34.2.71

Parsell, C., Petersen, M., & Moutou (2015). Single-site supportive housing: Tenant perspectives. *Housing Studies, 30*(8), 1189-1209. https://doi.org/10.1080/02673037.2015.1009874

Patanwala, M., Tieu, L., Ponath, C., Guzman, D., Ritchie, C. S., & Kushel, M. (2017). Physical, psychological, social, and existential symptoms in older homeless-experienced adults: An observational study of the HOPE-HOME cohort. *Journal of General Internal Medicine: JGIM*, *33*(5), 635-643. https://doi.org/10.1007/s11606-017-4229-1

Paul Jr, D. W., Knight, K. R., Olsen, P., Weeks, J., Yen, I. H., & Kushel, M. B. (2020). Racial discrimination in the life course of older adults experiencing homelessness: results from the HOPE HOME study. *Journal of Social Distress and Homelessness*, *29*(2), 184-193. https://doi.org/10.1080/10530789.2019.1702248

Pauwels, L. (2015). *Reframing visual social science: Towards a more visual sociology and anthropology*. Cambridge, United Kingdom: Cambridge University Press. https://doi.org/10.1080/1472586X.2017.1320088

Perry, T. E. (2014). Moving as a gift: Relocation in older adulthood. *Journal of aging studies*, *31*, 1-9. https://doi.org/10.1016/j.jaging.2014.07.001

Perry, T., Berglund, L., Mah, J., Sanford, C., Schaeffer, P., & Villeneuve, E. W. (2021). Advocating for the preservation of senior housing: A coalition at work amid gentrification in Detroit, Michigan. *Housing Policy Debate*, *31*(2), 254-273. https://doi.org/10.1080/10511482.2020.1806899

Petersen, M (2020). Rural ageing, housing, and homelessness In Skinner, M., Winteron, R., & Walsh, K. (Eds). *Rural gerontology: Toward critical perspectives on rural ageing*. Routledge. https://doi.org/10.4324/9781003019435

Phillippi, J., & Lauderdale, J. (2018). A guide to field notes for qualitative research: Context and conversation. *Qualitative Health Research, 28*(3), 381-388. https://doi.org/10.1177/1049732317697102

Phillips, D. & Kuyini, A.B. (2018). Consumer participation in specialist homelessness services: Do the homeless have a say in the services they receive? *International Social Work, 61*(6), 1095-1115. https://doi.org/10.1177/0020872817695644

Piepzna-Samarasinha, L.L. (2018). *Care work: Dreaming disability justice*. Vancouver: Arsenal Pulp Press.

Plotnikova, S. (20 Apr 2022). A cage by another name. *Failed Architecture*. Retrieved on 29 May 2022 from https://failedarchitecture.com/a-cage-by-another-name/.

Poo, A.J. (2015). *The age of dignity: Preparing for the elder boom in a changing America*. New York, New York: The New Press.

Popay, J., Thomas, C., Williams, G., Bennett, S., Gatrell, A., & Bostock, L. (2003). A proper place to live: Health inequalities, agency, and the normative dimensions of space. *Social Science & Medicine, 57*(1), 55-69. https://doi.org/10.1016/S0277-9536(02)00299-X

Pratt, S. I., Van Citters, A. D., Mueser. K. T. & Bartles, S. J. (2008). Psychosocial rehabilitation on older adults with serious mental illness: A review of the research literature and recommendation for development of rehabilitative approaches.

American Journal of Psychiatric Rehabilitation, 11, 7–40 https://doi.org/10.1080/15487760701853276

Puar, J. K. (2017). *The right to maim: Debility, capacity, disability*. Durham: Duke University Press. ISBN 9780822372530

Pynoos, J. (2018). The future of housing for the elderly: Four strategies that can make a difference. *Public Policy & Aging Report, 28*(1), 35-38. https://doi.org/10.1093/ppar/pry006

Quinn K.L., Shurrab, M., Gitau, K., Kavalieratos, D., Isenberg, S.R., Stall, N.M., Stukel, T.A., Goldman, R., Horn, D., Cram, P., Detsky, A.S., Bell, C.M. (2020). Association of receipt of palliative care interventions with healthcare use, quality of life, and symptom burden among adults with chronic non-cancer illness: A systematic review and meta-analysis. *JAMA, 324*(14), 1439–1450. https://doi.org/10.1001/jama.2020.14205

Rainsford, S., MacLeod, R. D., Glasgow, N. J., Wilson, D. M., Phillips, C. B., & Wiles, R. B. (2018). Rural residents' perspectives on the rural 'good death': A scoping review. *Health & Social Care in the Community, 26*(3), 273-294. https://doi.org/10.1111/hsc.12385

Rankin, S.K. (2021). Hiding homelessness: The transcarceration of homelessness. *California Law Review, 109* (2), 559-614. Retrieved from https://heinonline-org.offcampus.lib.washington.edu/HOL/P?h=hein.journals/calr109&i=561 .

Redman-MacLaren, M., & Mills, J. (2015). Transformational grounded theory: Theory, voice, and action. *International Journal of Qualitative Methods, 14*(3), 1-12. https://doi.org/10.1177/160940691501400301

Regulations Relating to Housing and Urban Development, 24 C.F.R. § 576.2. https://www.law.cornell.edu/cfr/text/24/576.2

Rhoades, H., Wenzel, S. L., & Henwood, B. F. (2019). Changes in self-rated physical health after moving into permanent supportive housing. American Journal of Health Promotion, 33(7), 1073-1076 https://doi.org/10.1177/0890117119849004

Rollston, R., & Galea, S. (2020). COVID-19 and the Social Determinants of Health. *American Journal of Health Promotion*, *34*(6), 687-689. https://doi.org/10.1177/0890117120930536b

Rothwell, D. W., Sussman, T., Grenier, A., Mott, S., & Bourgeois-Guerin, V. (2016). Patterns of shelter use among men new to homelessness in later life: Duration of stay and psychosocial factors related to departure. *Journal of Applied Gerontology, 36*(1), 71-93. https://doi.org/10.1177/0733464815624154

Richard, M. K., Dworkin, J., Rule, K. G., Farooqui, S., Glendening, Z., & Carlson, S. (2022). Quantifying Doubled-Up Homelessness: Presenting a New Measure Using US Census Microdata. *Housing Policy Debate*, 1-22. https://doi.org/10.1080/10511482.2021.1981976

Riedl, M., Mantovan, F., & Them, C. (2013). Being a nursing home resident: A challenge to one's identity. *Nursing Research and Practice*. https://doi.org/10.1155/2013/932381

Robinson, O. C. (2014). Sampling in interview-based qualitative research: A theoretical and practical guide. *Qualitative Research in Psychology*, *11*(1), 25-41. https://doi.org/10.1080/14780887.2013.801543

Rog, D.J., Marshall, T., Doughtery, R.H., George, P., Daniels, A.S., Ghose, S.S., & Delphin-Rittmon, M.E. (2014). Permanent supportive housing: Assessing the evidence. *Psychiatric Services, 65*(3), 287-294. https://doi.org/10.1176/appi.ps.201300261

Romaszko, J., Cymes, I., Dragańska, E., Kuchta, R., & Glińska-Lewczuk, K. (2017). Mortality among the homeless: Causes and meteorological relationships. *PloS One, 12*(12), e0189938. https://doi.org/10.1371/journal.pone.0189938

Romero, A. P., Goldberg, S. K., & Vasquez, L. A. (Apr 2020). LGBT people and housing affordability, discrimination, and homelessness. *UCLA School of Law Williams Institute*. https://escholarship.org/content/qt3cb5b8zj/qt3cb5b8zj.pdf

Rosenheck, R. (2021). Medicalizing homelessness: Mistaken identity, adaptation to conservative time, or revival of social medicine. *Medical Care, 59,* 106-109, https://doi.org/10.1097/MLR.0000000000001366

Rota-Bartelink, A., & Lipmann, B. (2007). Supporting the long-term residential care needs of older homeless people with severe alcohol-related brain injury in Australia: The Wicking Project. *Care Management Journals, 8*(3), 141. https://doi.org/10.1891/152109807781753763

Sbaraini, A., Carter, S. M., Evans, R. W., & Blinkhorn, A. (2011). How to do a grounded theory study: a worked example of a study of dental practices. *BMC Medical Research Methodology, 11*(1), 128-128. https://doi.org/10.1186/1471-2288-11-128

Scallan, E., Bodkin, C., Wiwcharuk, J., O'Shea, T., & Lennox, R. (2022). Finding stability amidst the COVID-19 pandemic: The impact of emergency temporary housing for people who use drugs. *Drug and Alcohol Review*, *41*(1), 7-8. https://doi.org/10.1111/dar.13335

Schneider, M., Brisson, D., & Burnes, D. (2016). Do we really know how many are homeless?: An analysis of the point-in-time homelessness count. *Families in Society*, *97*(4), 321-329. https://doi.org10.1606/1044-3894.2016.97.39

Schneider, E. & Dosani, N. (2021). Retrospective study of a Toronto-based palliative care program for individuals experiencing homelessness. *Journal of Palliative Medicine, 24*(8), 1232-1235. https://doi.org/10.1089/jpm.2020.0772

Schweik, S.M. (2009). *The ugly laws: Disability in public*. NYU Press.

Scutella, R., Wood, G., & Johnson, G. (2020). Sitting in the waiting room: Do people experiencing homelessness underutilize health services? *Housing & Society, 48*(3), 261-291. https://doi.org/10.1080/08882746.2020.1835116

Seixas, N. S., Blecker, H., Camp, J., & Neitzel, R. (2008). Occupational health and safety experience of day laborers in Seattle, WA. *American Journal of Industrial Medicine*, *51*(6), 399-406. https://doi.org/10.1002/ajim.20577

Serge, L., & Gnaedinger, N. (2003). Housing options for elderly or chronically ill shelter users: Final report (No. CMHCC. R. File No. 6530-62). Ottawa: Research Division: Canadian Mortgage and Housing Corporation.

Shalev, D., Fields, L., & Shapiro, P. A. (2020). End-of-life care with individuals with serious mental illness. *Psychosomatics (Washington, D.C.)*, *61*(5), 428-435. https://doi.org/10.1016/j.psym.2020.06.003

Sharma, H., Perraillon, M. C., Werner, R. M., Grabowski, D. C., & Konetzka, R. T. (2020). Medicaid and nursing home choice: Why do duals end up in low-quality facilities? *Journal of Applied Gerontology, 39*(9), 981-990. https://doi.org/10.1177/0733464819838447

Sharp, G., & Hall, M. (2014). Emerging forms of racial inequality in homeownership exit, 1968–2009. *Social Problems, 61*(3), 427-447. https://doi.org/10.1525/sp.2014.12161

Shelton, J., DeChants, J., Bender, K., Hsu, H. T., Maria, D. S., Petering, R., & Barman-Adhikari, A. (2018). Homelessness and housing experiences among LGBTQ young adults in seven US cities. *Cityscape*, *20*(3), 9-34. https://doi.org./174.127.242.42

Shields, R. (1992). *Places on the margin: Alternative geographies of modernity*. Psychology Press. https://doi.org/10.4324/9781315003269

Shulman, C., Hudson, B. F., Low, J., Hewett, N., Daley, J., Kennedy, P., & Stone, P. (2018). End-of-life care for homeless people: A qualitative analysis exploring the challenges to access and provision of palliative care. *Palliative Medicine*, *32*(1), 36-45. https://doi.org/10.1177/0269216317717101

Simpson, A. (2007). On ethnographic refusal: indigeneity, 'voice' and colonial citizenship. *Junctures: The Journal for Thematic Dialogue* (9), 67-80.

Simpson, A. (2014*). Mohawk interruptus: Political life across the borders of settler states*. Duke University Press. https://doi.org/10.1515/9780822376781

Singh, A., Daniel, L., Baker, E., & Bentley, R. (2019). Housing disadvantage and poor mental health: A systematic review. *American Journal of Preventive Medicine*, *57*(2), 262-272. https://doi.org/10.1016/j.amepre.2019.03.018

Sixsmith, J., Fang, M. L., Woolrych, R., Canham, S., Battersby, L., Ren, T. H., & Sixsmith, A. (2019). Ageing-in-place for low-income seniors: Living at the intersection of multiple identities, positionalities, and oppressions. In *The Palgrave handbook of intersectionality in public policy*. Palgrave Macmillan.

Smith, C., & Castañeda-Tinoco, E. (2019). Improving homeless point-in-time counts: Uncovering the marginally housed. *Social Currents*, *6*(2), 91-104. https://doi.org/10.1177/2329496518812451

Smith, A. K., Thai, J. N., Bakitas, M. A., Meier, D. E., Spragens, L. H., Temel, J. S., & Rabow, M. W. (2013). The diverse landscape of palliative care clinics. *Journal of Palliative Medicine*, *16*(6), 661-668. https://doi.org/10.1089/jpm.2012.0469

Smyth, F. (2005). Medical geography: Therapeutic places, spaces, and networks. *Progress in Human Geography*, 29(4), 488-495. https://doi.org/10.1191/0309132505ph562pr

Snyder, S. L., & Mitchell, D. T. (2015). *The biopolitics of disability: Neoliberalism, ablenationalism, and peripheral embodiment*. Ann Arbor: University of Michigan Press. ISBN: 0472072714

Song J, Bartels DM, Ratner ER (2007). Dying on the streets: Homeless persons' concerns and desires about end-of-life care. *Journal of General Internal Medicine, 22*, 435–41. http://dx.doi.org/10.1007/s11606-006-0046-7

Speer, J. (2019). Urban makeovers, homeless encampments, and the aesthetics of displacement. *Social & Cultural Geography*, *20*(4), 575-595. https://doi.org/10.1080/14649365.2018.1509115

Stajduhar, K. I., Mollison, A., Giesbrecht, M., McNeil, R., Pauly, B., Reimer-Kirkham, S., & Rounds, K. (2019). "Just too busy living in the moment and surviving": Barriers to accessing health care for structurally vulnerable populations at end-of-life. *BMC Palliative Care*, *18*(1), 11-11. https://doi.org/10.1186/s12904-019-0396-7

Sternberg, E. M. (2010). *Healing spaces: The science of place and well-being*. Harvard University Press. ISBN: 0674057481

Stevens, S. (2022). Leper islands: Coronavirus and the homeless 'other'. In Price, S. & Harbisher, B. (Eds). *Power, media, and the Covid-19 pandemic: Framing public discourse*. New York: Routledge. https://doi.org/10.4/324/9781003147299

Stone, R.I. (2018). The housing challenges of low-income older adults and the role of federal policy. *Journal of Aging & Social Policy, 30*(3-4), 227-243. https://doi.org/10.1080/08959420.2018.1462679

Strauss, A. L., & Glaser, B. G. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine Publishing. https://doi.org/10.4324/9780203793206

Sullivan, B., & Burke, J. (2013). Single-room occupancy housing in New York City: The origins and dimensions of a crisis. *CUNY Law Review, 17*(1), 113. https://heinonline.org/HOL/P?h=hein.journals/nyclr17&i=119

Sumalinog, R., Harrington, K., Dosani, N., & Hwang, S. W. (2017). Advance care planning, palliative care, and end-of-life care interventions for homeless people: a systematic review. *Palliative Medicine, 31*(2), 109-119. https://doi.org/10.1177/0269216316649334.

Suri, H. (2011). Purposeful sampling in qualitative research synthesis. *Qualitative Research Journal*, *11*(2), 63-75. https://doi.org/10.3316/QRJ1102063

Sylvestre, J. (2017). The contributions of the concept of citizenship to housing practice, policy, and research. In Slyvestre, Nelson, & Aubry (Eds). *Housing, citizenship, and communities for people with serious mental illness: Theory, research,* *practice, and policy perspectives*. New York: Oxford University Press. https://doi.org/10.1093/acprof:oso/9780190265601.003.0007

Tabol, C., Drebing, C., & Rosenheck, R. (2010). Studies of "supported" and "supportive" housing: A comprehensive review of model descriptions and measurement. *Evaluation and Program Planning, 33*(4), 446-456. https://doi.org/10.1016/j.evalprogplan.2009.12.002

Tavener, M., Byles, J., & Loxton, D. (2014). Expert perceptions of the popular Baby Boomer image. *Australasian Journal on Ageing*, *33*(4), 31-35. https://doi.org/10.1111/ajag.12087

Taylor, J., Swetenham, K., Myhill, K., Glaetzer, K., Picot, S., & van Loon, A. (2012). IMhPaCT: An education strategy for cross-training palliative care and mental health clinicians. *International Journal of Palliative Nursing, 18*(6), 290-294. https://doi.org/10.12968/ijpn.2012.18.6.290

Taylor, L.A. (2018). How do we fund flourishing? Maybe not through health care. *Hastings Center Report, 48*(5), 62-66. https://doi.org/10.1002/hast.916

Taylor, S. P. (2018). Critical realism vs social constructionism & social constructivism: application to a social housing research study. *International Journal of Sciences: Basic and Applied Research*, *37*(2), 216-222. https://insight.cumbria.ac.uk/id/eprint/3596

Teno, J. M., Gozalo, P., Trivedi, A. N., Bunker, J., Lima, J., Ogarek, J., & Mor, V. (2018). Site of death, place of care, and health care transitions among US Medicare beneficiaries, 2000-2015. *JAMA, 320*(3), 264-271. https://doi.org/10.1001/jama.2018.8981

Thrift, N. (1999). The place of complexity. *Theory, Culture & Society, 16*(3), 31-69.

Thrush. (2017). *Native Seattle: Histories from the crossing-over place* (Second Eds). University of Washington Press. ISBN: 9780295988122

Tobey, M. M. D., Manasson, J. M. D., Decarlo, K. M. D., Ciraldo-Maryniuk, K. M. D., Gaeta, J. M. M. D., & Wilson, E. M. D. (2017). Homeless Individuals Approaching the End of Life: Symptoms and Attitudes. *Journal of Pain and Symptom Management*, *53*(4), 738-744. https://doi.org/10.1016/j.jpainsymman.2016.10.364

Torres-Gil, F., & Hofland, B. (2012). Vulnerable populations. In H. Cisneros, M. Dyer, Chamberlain, & J. Hickie (Eds). *Independent for life: Homes and neighborhoods for an aging America*. Austin: University of Texas Press. ISBN 9780292737914

Tsai, J., Link, B., Rosenheck, R. A., & Pietrzak, R. H. (2016). Homelessness among a nationally representative sample of US veterans: prevalence, service utilization, and correlates. *Social Psychiatry and Psychiatric Epidemiology*, *51*(6), 907-916. https://doi.org/10.1007/s00127-016-1210-y

Tsai, J., & Gu, X. (2019). Homelessness among immigrants in the United States: Rates, correlates, and differences compared with native-born adults. *Public Health*, *168*, 107-116. https://doi.org/10.1016/j.puhe.2018.12.017

Tuan, Y.-F. (1977). *Space and Place: The Perspective of Experience*. University of Minnesota Press. ISBN 9780713159714

U.S. Department of Housing and Urban Development (1 Apr 2016). What are the main differences between the previous definition of “chronically homeless” and the definition included in the final rule? Retrieved on 10 Apr 2022 from https://www.hudexchange.info/faqs/programs/continuum-of-care-cocprogram/program-requirements/definition-of-chronic-homelessness/what-are-the-main-differences-between-the-previous-definition-of/

U.S. Department of Housing and Urban Development (18 Mar 2021). 2020 Annual Homeless Assessment Report to Congress: Part I- Point-in-Time Estimates of Homelessness in the U.S. Retrieved on 10 Apr 2022 from https://www.huduser.gov/portal/datasets/ahar/2020-ahar-part-1-pit-estimates-of-homelessness-in-the-us.html

U.S. Department of Housing and Urban Development (n.d.). Assisted living conversion program (ALCP). Retrieved on 25 Mar 2022 from https://www.hud.gov/program_offices/housing/mfh/progdesc/alcp

Van Walraven, C., Oake, N., Jennings, A., & Forster, A. J. (2010). The association between continuity of care and outcomes: A systematic and critical review. *Journal of Evaluation in Clinical Practice*, *16*(5), 947-956. https://doi.org/10.1111/j.1365-2753.2009.01235.x

Vassar, M., & Holzmann, M. (2013). The retrospective chart review: important methodological considerations. Journal of Educational Evaluation for Health Professions, 10, 12. https://doi.org/10.3352/jeehp.2013.10.12

Wadhera, R. K., Choi, E., Shen, C., Yeh, R. W., & Joynt Maddox, K. E. (2019). Trends, causes, and outcomes of hospitalizations for homeless individuals: A retrospective cohort study. *Medical Care, 57*(1), 21–27. https://doi.org/10.1097/MLR.0000000000001015

Weare, C. (2019). Counting the Homeless: Improving Knowledge of the Unsheltered Homeless Population. *Center for Homeless Inquiries*. Retrieved from https://socialinnovation.usc.edu/wp-content/uploads/2019/12/Christopher-Weare-Counting-the-Homeless.pdf

Webb, W. A., Mitchell, T., Snelling, P., & Nyatanga, B. (2020). Life's hard and then you die: the end-of-life priorities of people experiencing homelessness in the UK. *International Journal of Palliative Nursing*, *26*(3), 120-132. https://doi.org/10.12968/ijpn.2020.26.3.120

West S.K., Levi, L. (2004). Culturally appropriate end-of-life care for the Black American. *Home Healthcare Nurse, 22*(3), 164-168. https://doi.org/10.1097/00004045-200403000-00007

Westbrook, M. & Robinson, T. (2021). Unhealthy by design: Health & safety consequences of the criminalization of homelessness. *Journal of Social Distress and Homelessness, 30*(2), 107-115. https://doi.org/10.1080/10530789.2020.1763573

Westneat, D. (26 Mar 2022). Volunteers fly into Seattle's spider web on homelessness. *Seattle Times*. https://www.seattletimes.com/seattle-news/politics/volunteers-fly-into-seattles-spider-web-on-homelessness/

Whatcott, J. (2021). Sexuality, disability, and madness in California's eugenics era. In Shuttleworth, R. & Mona, L. (Eds). *Routledge handbook of disability and sexuality*. London: Routledge. ISBN 9781138593237

White, B. M., & Newman, S. D. (2015). Access to primary care services among the homeless: a synthesis of the literature using the equity of access to medical care framework. *Journal of Primary Care & Community Health, 6*(2), 77-87. https://doi.org/10.1177/2150131914556122

Williams, J.C. (2011). “Stand up and be counted”: The politics of a homeless enumeration. *Poverty & Public Policy 3*(3), 1–27. https://doi.org/10.2202/1944-2858.1172

Willse, C. (2015). *The value of homelessness: Managing surplus life in the United States*. University of Minnesota Press. ISBN 9780816693474

Wilson, B., Choi, S.K, Harper, G.W., Lightfoot, M., Russell, S., Meyer, I.H. (May 2020). Homelessness among LGBT adults in the US. *UCLA Williams Institute*. Retrieved from https://escholarship.org/content/qt9kp233rh/qt9kp233rh.pdf

Wong, A., Chen, J., Weiss, D., Sleet, D.A., & Francescutti, L.H. (2020). Combatting homelessness in Canada: Applying lessons learned from six Tiny Villages to Edmonton Bridge Healing Program. *International Journal of Environmental Research and Public Health, 17*, 6279. https://doi.org/10.3390/ijerph17176279.

Yu, S. W., Hill, C., Ricks, M. L., Bennet, J., & Oriol, N. E. (2017). The scope and impact of mobile health clinics in the United States: a literature review. *International Journal for Equity in Health, 16*(1), 1-12. https://doi.org/10.1186/s12939-017-0671-2

Yunus, A. & Doore, S.A. (9 Dec 2021). Responsible use of agile robots in public spaces. *International Symposium on Ethics in Engineering, Science & Technology*. https://doi.org/10.1109/ETHICS53270.2021.9632682

Zarem, J. E. (2010). Today’s continuing care retirement community (CCRC). CCRC Task Force, American Seniors Housing Association. Retrieved from https://www.naccrau.com/RGHyland/AAHSA%20on%20CCRC%20Characteristics.pdf

APPENDICES

Appendix A

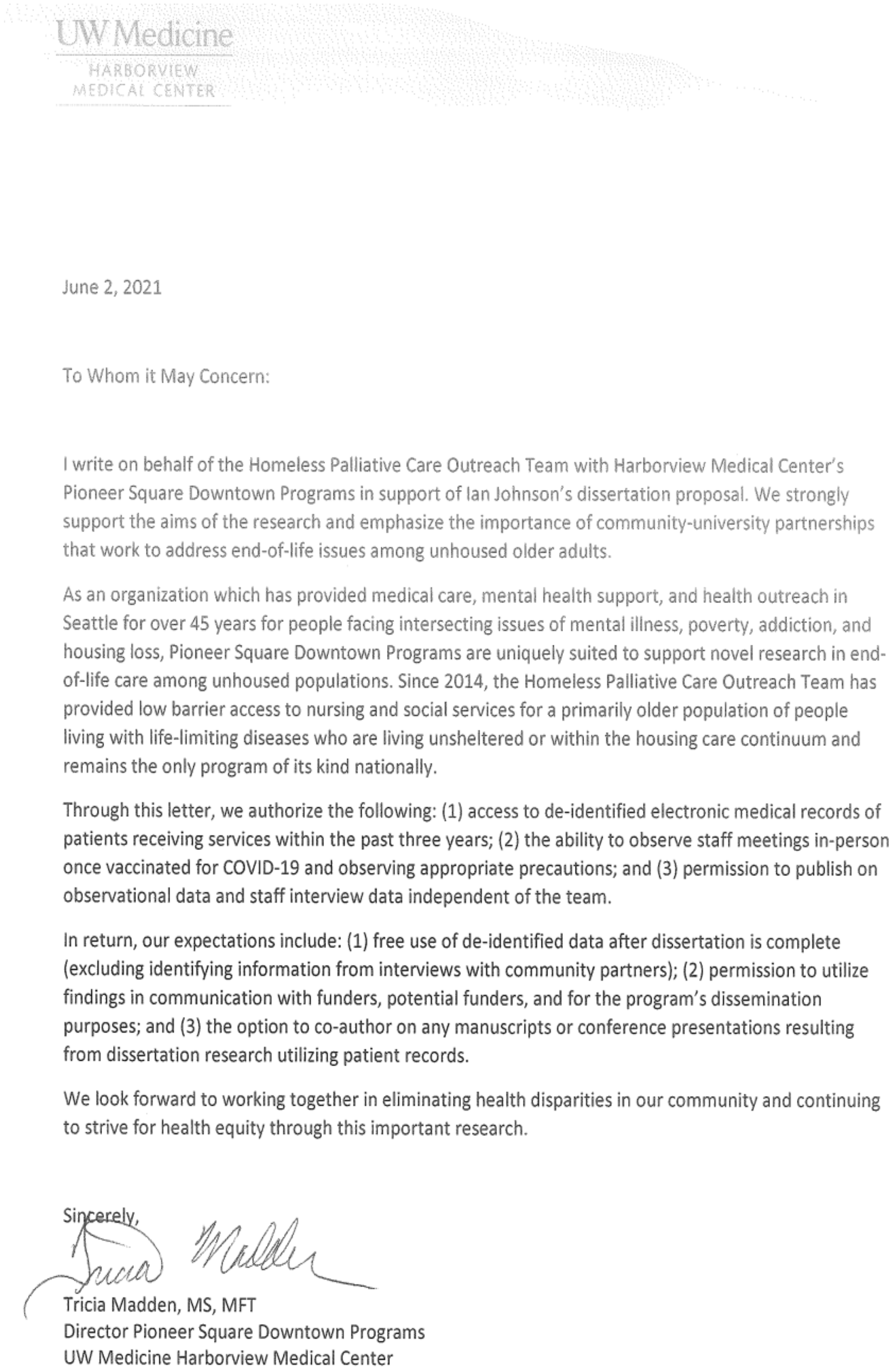
Housing care options in the United States

Type of Housing	Description
Permanent Housing	
Permanent Supportive Housing	Permanent housing in which housing agencies may (a) receive subsidies to lease apartments on the private housing market and sublease them to consumers with a range of visiting supportive services; and/or (b) construct, own and operate entire buildings with on-site supportive services to promote housing stability (HUD, n.d.). Rent is subsidized for residents and eligibility standards require the presence of at least one of the following: history of homelessness; history of incarceration; diagnoses of serious mental illness (e.g., schizophrenia, bipolar disorder), substance use disorder, and/or HIV/AIDS (SAMHSA, n.d)
Supported Housing Programs	Funding mechanisms and sites designed to provide housing access including Section 8 vouchers, rapid re-housing, low-income housing, and senior housing. Sometimes equipped or co-located with health and social service programming
Temporary Accommodations	
Emergency Shelter	Overnight sleeping accommodations in group setting; may operate as a 24-hour center for guests, provide day services, or only operate overnight; may require referral or drop-in only services (HUD, n.d.). Does not require a lease or other residential agreements.
Sanctioned Encampments / Tiny Villages	A group of people experiencing homelessness that have time-limited land use permits to reside in vehicles, tents, and/or tiny homes on public land (National Coalition for the Homeless, n.d.). Tiny homes are mobile micro-dwellings weatherproofed for outdoor insulation and enough interior space for personal storage and a bed, often implemented with supportive housing oversight in ‘village’ clusters with on-site case management and centralized kitchen and bathroom areas (Heben, 2014)
Transitional Housing	Provides housing and appropriate supportive services to homeless persons to facilitate movement to independent living within 24 months (HUD, n.d.)
Medical Respite	Short-term acute and post-acute residential care for individuals experiencing homelessness to rest in a safe environment while accessing medical care and other supportive services; offered in a variety of settings including freestanding facilities and shelters (National Healthcare for the Homeless Council, n.d.)
Single Resident Occupancy Units (SRO)	A single room, usually less than 100 square feet, designed to accommodate one person with amenities such as a bathroom, kitchen or common areas located outside the unit and shared with other residents (Housing Consortium, n.d.)
Private Pay Hotels	Hotels/motels paid for directly by the occupant daily, weekly, or for extended stay
Healthcare Institutions	

Skilled Nursing Facilities/ Rehabilitation Centers	Short- or long-term residential care for people needing personal and medical care and/or rehabilitation (NIA, 2017)
Adult Family Homes / Group Homes/ Adult Foster Care	Independently owned and operated private residential homes that house and provide 24-hour custodial care to 1-8 people at a time
Carceral Institutions	
Residential Psychiatric and/or Drug Treatment	A short- or long-term environment for 24-hour supervised and structured treatment of serious mental illness or substance abuse (ARTA, 2022; NIDA, 2018)
Jail	Facility run by city or county law enforcement and government agencies designed for short-term stays for those awaiting trial or serving short misdemeanor sentences (Kang-Brown et al., 2021)
Prison	Secured centers under the jurisdiction of state or federal government where those convicted of crimes are detained (Kang-Brown et al., 2021)
Other Sleeping Places	
Places Not Meant for Human Habitation	May include cars, boats, RVs, parks, sidewalks, abandoned buildings, unsanctioned camps, or on the street (HUD, n.d.)
Doubled Up / Couchsurfing	Individuals temporarily housed with an informal contact (friend, family, etc.) without a lease, and is otherwise “at risk” for homelessness

Appendix B

Memorandum of Understanding



UW Medicine
HARBORVIEW
MEDICAL CENTER

June 2, 2021

To Whom it May Concern:

I write on behalf of the Homeless Palliative Care Outreach Team with Harborview Medical Center's Pioneer Square Downtown Programs in support of Ian Johnson's dissertation proposal. We strongly support the aims of the research and emphasize the importance of community-university partnerships that work to address end-of-life issues among unhoused older adults.

As an organization which has provided medical care, mental health support, and health outreach in Seattle for over 45 years for people facing intersecting issues of mental illness, poverty, addiction, and housing loss, Pioneer Square Downtown Programs are uniquely suited to support novel research in end-of-life care among unhoused populations. Since 2014, the Homeless Palliative Care Outreach Team has provided low barrier access to nursing and social services for a primarily older population of people living with life-limiting diseases who are living unsheltered or within the housing care continuum and remains the only program of its kind nationally.

Through this letter, we authorize the following: (1) access to de-identified electronic medical records of patients receiving services within the past three years; (2) the ability to observe staff meetings in-person once vaccinated for COVID-19 and observing appropriate precautions; and (3) permission to publish on observational data and staff interview data independent of the team.

In return, our expectations include: (1) free use of de-identified data after dissertation is complete (excluding identifying information from interviews with community partners); (2) permission to utilize findings in communication with funders, potential funders, and for the program's dissemination purposes; and (3) the option to co-author on any manuscripts or conference presentations resulting from dissertation research utilizing patient records.

We look forward to working together in eliminating health disparities in our community and continuing to strive for health equity through this important research.

Sincerely,

Tricia Madden

Tricia Madden, MS, MFT
Director Pioneer Square Downtown Programs
UW Medicine Harborview Medical Center

Appendix C

Data retrieval form

Variable	Description
Length of stay	Number of days at each site of care
Length of enrollment	Number of days of enrollment with Homeless Pall Care services
Number of transitions within facility	Documented transitions between care settings within a particular institution (e.g., ER to ICU)
Number of transitions during program enrollment	Documented transitions during enrollment with Homeless Pall Care Team
Distance from last location	Number of miles from last location
Place of death	Site where patient's death was documented
Referral denied	Staff documented a referral to services was denied
Referral denied, reason	Documented reason for service denial
Preferred place of care mentioned	Pt and staff had a documented conversation about preferred place of care
Reasons prompting care transition	Documented information regarding what prompted care transition
Treatment adherence barriers	Staff documented a barrier to patient receiving medically appropriate and desired services, referrals
Care provision barriers	Staff documented a barrier to accessing patient and providing Homeless Pall Care team services

Treatment/care facilitated	Documented uptake of biopsychosocial services upon intake to care
Place implications for legacy work	Place is documented in service narrative surrounding legacy work
Place implications for discharge	Place is documented in service narrative surrounding discharge, aftercare, collaborative contact postmortem

Appendix D

Interview disclosure and question guide

KEY INFORMATION ABOUT THIS STUDY

Purpose: The purpose of this study (STUDY 00013488) is to understand where facilitators and barriers manifest in palliative care with unhoused patients and the impact of those facilitators and barriers on end-of-life residential and care trajectories. These interviews will be paired with observational data of the Harborview Homeless Palliative Care team and retrospective chart review. Topics of in the interview include general observations about the facilitators and barriers to patient-centered care for unhoused people in your setting, information about how you partner with others in the network of services, barriers in your setting for unhoused patients, the impact of COVID-19 on care for unhoused patients in your setting, and your recommendations for enhancing patient care.

Procedures: I am recruiting to direct service providers in community organizations who have partnered with the team around patient care. Interviews with community partners will take approximately 30-45 minutes and will be conducted over the phone or via Zoom. Interviews will be recorded and professionally transcribed. All information will be kept confidential and will be de-identified after transcripts are reviewed.

Risks & Benefits: There are no tangible benefits from participation in the study. Mild distress may be experienced from recalling barriers to unhoused patients' care. You may refuse to participate, and you are free to withdraw from this study at any time without penalty. If you wish to withdraw, please contact me at ianmj@uw.edu or 585-506-7435. If you think you have been harmed from being in this research, contact Taryn Lindhorst at tarynlin@uw.edu or directly contact the University IRB at (206) 543-0098 or collect at (206) 221-5940.

Researcher Disclosures: The study team does not receive financial support from Harborview, University of Washington, or any outside sources.

- What is your role when working with people receiving palliative care?
- What does the mobile palliative care team do for patients in your setting?
- What are the barriers for care in your setting(s) with older or seriously ill unhoused patients?
- Where do you see patients come from / go to in your setting?

- What does your service and/or setting offer that is a unique benefit to unhoused patients?
- What has the impact of COVID-19 been on your care with unhoused patients?
    - Prompt (if applicable): referrals to your setting, advanced care planning, treatment options, discharge planning if not addressed directly
- How has COVID-19 changed your collaboration with the mobile palliative care team?
- What recommendations do you have to enhance patient care?
    - Prompt (if applicable): What is your org/industry/team working on to improve practices and polices?
- What recommendations do you have to enhance provider collaboration?