“Care is Connection”: How Place Shapes Experiences of Care for Precariously Housed Adults Nearing End-of-Life

by

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A Thesis Submitted in Partial Fulfillment of the
Requirements for the Degree of

MASTER OF ARTS

In the School of Public Health and Social Policy

University of Victoria

We acknowledge and respect the Lək^{w}əŋən (Songhees and X^{w}sepsəm/ Esquimalt) Peoples on whose territory the university stands, and the Lək^{w}əŋən and W̱ SÁNEĆ Peoples whose historical relationships with the land continue to this day.

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Abstract

As the social determinants of health literature highlight, housing is more than a physical space; it is a critical foundation for social connectivity and healthcare access. Stable housing supports the development of community connections, which are linked to enhanced well-being and a better quality of life. Furthermore, these connections fulfill a vital function in the context of end-of-life care. Conversely, for adults who are precariously housed, inadequate housing may disrupt the ability to engage with their communities, resulting in social isolation and adverse end-of-life care experiences. As such, housing stability plays a vital role in facilitating or limiting social connections. Drawing on observational fieldnotes and qualitative interviews, this study examined the role of 'place' in shaping experiences of care for unstably housed adults nearing end-of-life guided by a geographic and health equity lens. The findings reveal that social connection and supportive relationships were seen as central to participants' sense of home and experiences of care. Meanwhile, displacement and frequent transitions illustrate how disrupted connections can impact quality of life and restrict access to social support at end-of-life. In conclusion, this study underscores the significance of social connection, community support and sense of place in fostering more equitable end-of-life care experiences for precariously housed adults.

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Acknowledgements

I am deeply grateful for this process, not only for the work I have engaged in and the opportunities I have been given but also for the people who have surrounded me. Each of you has shaped so many parts of who I am and reinforced the values that I hold.

To my supervisors, Dr. Kelli Stajduhar, Dr. Denise Cloutier, and Dr. Damien Contandriopoulos – thank you for your time, effort, and mentorship. I feel incredibly fortunate to have had such a positive and supportive learning experience throughout this degree. I am also deeply appreciative of the ways in which you've challenged me and pushed me to grow.

Ashley – thank you for being my biggest supporter and sounding board, and for being so generous with your time. I can't fully express how much it has meant to learn from you.

To all of the amazing women who have cheered me on — Amber, Ami, Carley, Carren, Char, Kara, Kris, Melissa and Samara — thank you. I feel so lucky to work alongside you.

Mom, Dad, and Max – thank you for listening, learning, and always encouraging me to succeed, while giving me both the space and time to do so.

Jewels, Issy, Ava and Julia – my closest friends! I couldn't have done it without you.

Chapter 1: Introduction

Overview

The social determinants of health encompass a broad range of social and economic factors, such as income, education, employment, housing, and social inclusion, that collectively shape individual and population health outcomes (Rolfe et al., 2020). Braveman and Gottlieb (2014) also describe these determinants as the conditions into which we are born, grow, work, age, and ultimately die. Among them, housing plays a particularly significant role, not only as a physical space but as a foundation for social connection, access to care, and overall quality of life.

Housing stability is closely linked to health outcomes, with safe, well-located housing enabling access to essential services such as healthcare, transportation, and green spaces (Levasseur et al., 2015). More than just a shelter, housing also facilitates social connection, an often-overlooked determinant of health (Pivodic et al., 2024). Research indicates that stable living environments promote stronger community ties, enabling individuals to maintain relationships with family, neighbours, and caregivers (Kuboshima & McIntosh, 2023). Hosting visitors, cohabiting with partners, and engaging in neighbourhood activities have all been associated with improved well-being and longevity (Levasseur et al., 2015). Conversely, inadequate housing can disrupt social connections, contributing to isolation and stress, which are linked to poorer health outcomes, including increased risk of chronic illnesses (e.g., cardiovascular disease, respiratory conditions, and diabetes), higher prevalence of mental health disorders, reduced access to healthcare, heightened vulnerability to infectious diseases, and overall increased mortality rates (Swope & Herndandez, 2019).

For those nearing the end-of-life, the intersection of housing, social connection, and access to palliative care becomes particularly important. Most people prefer to die at home, surrounded by

their communities and social networks, a preference widely recognized as a measure of quality end-of-life care (Gomes et al., 2013). However, for those experiencing housing instability, being cared for and dying at home is rarely an option (Stajduhar et al., 2024). The latest report from the Canadian Institute for Health Information (CIHI, 2023) highlights persistent disparities in end-of-life care for adults facing housing precarity. Studies indicate that those without stable housing encounter numerous barriers to palliative care, including difficulty accessing healthcare providers, fragmented social support, and high levels of displacement near the end-of-life (Stajduhar et al., 2020). As a result, many precariously housed adults die in institutional settings or on the margins of the healthcare system, disconnected from the social and emotional support that contributes to a dignified death (Stajduhar, et al., 2019). Given these challenges, there is a pressing need to explore how place-based barriers affect end-of-life experiences for precariously housed populations, while also identifying facilitators that strengthen social connection and improve access to care.

The overall aim of my Master's thesis research was to investigate how 'place' shaped experiences of end-of-life care for precariously housed adults. In this chapter, I will begin by defining how the idea of place and the home environment is conceptualized, followed by a review of the literature focusing on the intersection of housing instability and palliative care access, the reliance on informal caregivers in Canada, the importance of social connection, and the role of place-based barriers in shaping social healthcare access. I then outline my research approach, focusing on the lived experiences of adults facing housing precarity at the end-of-life and my positionality within this work. Chapter Two is a planned submission to *The Journal of Health and Social Care in the Community* and, therefore, overlaps with some content covered in other chapters. Chapter Three highlights additional findings related to three key themes: 1) home

as social connection, 2) transitions and barriers to social connection and 3) pathways forward to fostering social connection. Finally, Chapter Four discusses the broader implications of these findings and concludes with actionable recommendations that focus on improving end-of-life care experiences for precariously housed adults.

Conceptualizing Place and Home

This thesis views the concept of 'place' as inherently dynamic and reliant on context, rather than as a fixed definition. Therefore, this fluid understanding of place provides a foundation for investigating diverse conceptualizations and definitions.

Researchers, particularly in the field of human geography, have explored the relationship between place and care, highlighting how environments influence the experiences of caregivers and the nature of care (Conradson, 2003; Milligan, 2016). A key approach to understanding place involves analyzing the physical and built environment, including how geographic location and proximity to health services influence both access to and provision of care (Gelormino et al., 2015). In its physical sense, place pertains to a material artifact, a specific location, or a setting for social interactions (Cresswell, 2014). Oswald and Wahl (2005) categorize a dwelling as both "a physical unit" and a "defined space for its residents", offering shelter and support for domestic activities (p.21). However, Hanrahan and Smith (2020) argue for the need to integrate relational aspects into the discussion of care geographies, asserting that care is shaped not only by physical attributes but also by the social relationships, politics, and power dynamics inherent within physical spaces.

Building on this perspective, other scholars similarly highlight that a sense of place extends beyond physical characteristics to include emotions, relationships, and lived experiences

within spaces (Cloutier et al., 2015; Convery et al., 2012; Eyles & Williams, 2016). Therefore, place is conceptualized as a multifaceted construct that includes material, political and social dimensions (Oswald & Wahl, 2005). By recognizing place as both a physical and socially constructed phenomenon, this framework highlights that place is not merely a backdrop for care but an active and evolving component of care relationships, influencing both caregivers and care recipients in complex and context-specific ways. This perspective is particularly relevant for precariously housed adults, for whom access to care is often determined by policies and systemic barriers embedded in the built and physical environment.

A particularly significant manifestation of place in the context of care is the concept of home. While home too lacks a singular definition, Oswald and Wahl (2005) argue that "the meaning of home on the most general level links the person with his or her environment" (p. 22). The connection between individuals and their environments becomes especially relevant in end-of-life care, where home is often framed as the ideal setting for caregiving. Seppänen, Niemi, and Sarivaara (2023) note that policies leveraging informal support systems have reinforced the notion that death has "returned home," with home increasingly recognized as a preferred site of care.

However, home is not always physically defined. Consistent with broader understandings of place, it often carries social, emotional, and relational significance, making it particularly relevant in discussions of housing instability and end-of-life care. Milligan (2016), drawing on Augé's (1995) conceptualization of "anthropological place," highlights home as a space of "connection, memory, and identity," underscoring its significance in shaping caregiving experiences (p. 69). She further argues that home enables individuals to exercise autonomy by "controlling decisions about who to admit or exclude" (p. 67). Additionally, home can provide

what Milligan (2016) describes as "ontological security" and a "safe space from the threats of the outside world" (p. 68). This sense of security and stability contributes to the broader understanding of home as a therapeutic environment, particularly for individuals who are ill or dying (Donovan & Williams, 2007). For those with histories of housing precarity, the significance of home in end-of-life care may be even more pronounced. Johnson et al. (2024) argue that "there may be an increased importance for care at home for people with histories of housing precarity," whatever home may mean to them (p. 2). While home can offer stability and comfort, its meaning is not universally positive. It can also evoke fear, abuse, neglect, or violence (Woodhall-Melnik et al., 2016). Furthermore, home may determine whether an individual receives care at all, highlighting the critical role of place in "mediating the availability of and access" to services (Milligan, 2016, p. 61).

Thus, understandings of home and place extend beyond the physical environment to consider how housing functions as a site of care, shaped by socio-political structures and relational dynamics. However, throughout this literature review, place and home are primarily examined in terms of how the physical environment influences access to care, with a more nuanced exploration of these concepts elaborated on in subsequent chapters.

Literature Review

Part 1: Palliative Care and Housing

According to the Government of Canada, palliative care is a "holistic approach that treats a person with serious illness of any age, and *in any setting*" (2024, p.1). In 2017, the passage of Bill C-277, *The Framework on Palliative Care in Canada Act*, marked a significant legislative advancement in the recognition and provision of palliative care across the country (Government of Canada, 2023). However, access to palliative care in Canada is often considered a privilege

rather than a universal right (Stajduhar et al., 2020; Williams et al., 2011). Most people who access palliative care tend to share similar socio-demographic and economic profiles (Stajduhar et al., 2019). They are typically diagnosed with conditions like cancer that follow more predictable disease trajectories, belong to dominant social groups, have strong family and community support networks, and are stably housed (Stajduhar et al., 2019; West et al., 2020). While barriers to end-of-life care still exist for non-marginalized populations, the increasing professionalization of palliative care has exacerbated challenges for marginalized groups, particularly those experiencing homelessness. This shift has moved care away from community-based hospices that once served the most vulnerable to a more clinically focused, institutionally driven system that has excluded those with more complex needs (Stajduhar et al., 2020). Studies highlight that factors such as unstable housing and the absence of consistent support significantly hinder access to care - resources that the healthcare system often considers necessary for receiving end-of-life care (Chan et al., 2024; Stajduhar et al., 2019).

In Canada, homelessness is defined as "the inability of an individual, family, or community to access or acquire stable, safe, permanent, and appropriate housing" (Fiorentino et al., 2023, p. 6). Moreover, it can be understood as a consequence of social and structural inequalities shaped by specific geographic contexts where rising costs of living, inadequate income support, and a lack of affordable housing contribute to housing insecurity (Canham et al., 2024). Throughout this discussion, the terms housing instability, housing insecurity, and housing precarity will be used interchangeably to reflect the broad spectrum of homelessness. In the context of this research, housing insecurity refers to the absence of stable, secure, and affordable housing (CMHC, 2022); housing instability points to the experience of frequent moves, evictions, or temporary housing (Kang, 2023); and housing precarity captures the broader sense

of vulnerability and uncertainty tied to inadequate housing conditions (Smith et al., 2024). I use these terms to emphasize the fluid and often precarious nature of housing among those nearing end-of-life while precariously housed.

The ongoing housing crisis in Canada has significantly contributed to rising homelessness rates, with serious implications for the health and well-being of precariously housed adults. According to Bryant (2016), the Canadian housing market is one of the least affordable in the world and has the "most private-sector dominated, market-based housing systems among Western nations" (p.361). Bryant (2016) further argues that in the case of Canadian housing policy, government's political ideologies are significant barriers to progressive housing policy change and that the "notion of collective social responsibility for vulnerable populations is no longer part of the political discourse" (p.377). This philosophy has, therefore, made it difficult to implement comprehensive, long-term housing solutions. Coupled with an increasing reliance on non-profit organizations to assume government responsibilities, this shift has weakened accountability, resulting in fragmented responses (Stephens, 2020). Milligan (2018) argues that this transition has contributed to the emergence of a shadow state, in which non-profit organizations, often operating with limited resources and unstable funding, are left to fill critical service gaps. As a result, housing and healthcare services for precariously housed adults remain underfunded and inconsistent. This has left many without access to stable and affordable housing, which has consequently exposed them to avoidable health risks stemming from poor living conditions and insufficient access to healthcare (Swope & Herndandez, 2020).

Hanssmann et al. (2022) emphasize that "housing is health care" (p. 45) and is one of the leading factors in health outcomes. Poor housing conditions, such as overcrowding, mould, and inadequate heating, are directly linked to physical health issues and can exacerbate chronic

illnesses (Rolfe et al., 2020). Housing precarity can also increase exposure to stress, harsh environmental elements, infectious diseases, and obstacles to accessing food and support services (Hanssmann et al., 2022; Rolfe et al., 2020). The impact on mental health is equally significant. Housing instability, fear of eviction, and lack of safety are sources of considerable psychological stress, often leading to or worsening mental health issues such as anxiety, depression, and PTSD (Bryant, 2016; Vásquez-Vera et al., 2017).

Moreover, chronic conditions that are usually well-managed in the general population are not treated effectively within homeless communities (Barnes, 2022). According to Webb (2021), adults experiencing homelessness are twice as likely to suffer from a long-term health condition yet are frequently marginalized and neglected in terms of healthcare provision. Numerous scholars characterize the health challenges encountered by people experiencing homelessness as "tri-morbidity," which is defined as the coexistence of mental health conditions, physical health conditions, and substance use (Barnes, 2022; Traynor, 2019). Barnes (2022) further argues that one-third of all deaths among adults experiencing homelessness are attributable to conditions that could be mitigated through appropriate healthcare interventions. Due to restricted access to healthcare services, many conditions commonly associated with older adults, such as frailty, incontinence, and dementia, are more prevalent among younger adults experiencing homelessness (Barnes, 2022). Compared to the general population, this group experiences significantly higher rates of premature mortality, with average ages at death ranging from 40 to 65 years (van Dongen et al., 2020). This variation stems from various factors such as socioeconomic status, healthcare access, substance use, and other social determinants of health. Mortality rate data come from several studies, including those by Beijer et al. (2011), Henwood et al. (2015), Hwang (2000), Hwang et al. (2009), Nielsen et al. (2011), and Nordentoft and

Wandall-Holm (2003), which emphasize how homelessness and chronic health conditions contribute to earlier mortality rates.

Despite the well-documented intersection of homelessness and poor health outcomes, people experiencing housing insecurity remain largely excluded from palliative and end-of-life care. Research reveals that it is nearly impossible for adults facing housing insecurity to access palliative care, often resulting in people dying alone in shelters, transitional housing, or in public spaces such as alleys, streets, and vehicles (Barnes, 2022; Stajduhar et al., 2019).

A key factor driving this exclusion is the requirement for stable housing, which presents a significant barrier to accessing palliative care services. Jenson et al. (2023) argue that eligibility for homecare and hospice services often hinges on having a fixed address, creating substantial obstacles for those without stable housing. Moreover, it's been noted that some providers refuse to offer care to patients who are precariously housed (Armstrong et al., 2021), raising critical questions about how institutions and healthcare providers define housing and what qualifies as "home" for different populations. Likewise, Purkey and MacKenzie (2019) highlight that individuals with severe medical conditions face obstacles to receiving care due to their housing status, often being denied certain treatments. The consequences of housing instability extend beyond initial eligibility for services. Johnson et al. (2023) argue that individuals often lose access to care when they experience housing transitions, such as entering precarious housing, being relocated, or displaced. This disruption can severely impact continuity of care, which is particularly crucial in end-of-life contexts. While homelessness and housing insecurity pose significant barriers to accessing palliative care, these challenges are further compounded by the healthcare system's reliance on informal caregiving, which assumes the availability of family support that may be absent for those experiencing housing instability.

Part 2: Informal Caregiving in Canada

Informal caregivers, typically family members providing unpaid care, are integral to the end-of-life care system in Canada, yet the healthcare system struggles to accommodate non-traditional family structures, who many precariously housed adults rely on for care (Schulz & Tompkins, 2010; West et al., 2020).

The Canadian Centre for Caregiving Excellence's 2024 report, *Caring in Canada*[1], highlights that in 2023, approximately two-thirds of caregivers were caring for a biologically related family member (parent, sibling, child, or other family member), underscoring the prevalence of family-based caregiving in Canada. However, not everyone has access to reliable and well-resourced social support and maintaining existing social supports and developing supportive connections may be more difficult for those precariously housed (Bower et al., 2023; Cummings et al., 2022). In line with findings by Mayerson and Hinrichs (2022), the estrangement of precariously housed adults from their bio-legal[2] families underscore a critical gap in traditional familial support structures for populations experiencing homelessness. For those not connected with their bio-legal family, this role is frequently filled by health and social

[1] Findings in this report are drawn from CCCE's first National Caregiving Survey, which was launched in July 2023. Many of the survey questions represent the first time that this data about caregiving is being captured in Canada. To develop the survey, CCCE worked closely with an advisory group of researchers with expertise in caregiving, as well as market research and analytics firm Leger. The survey collected information on caregiver and care provider demographics, care responsibilities, the impacts of caregiving on different dimensions of well-being and policy priorities. Between July and September 2023, the survey was administered in two ways: as a panel survey by Leger (conducted with caregivers within Leger's existing group of research participants) and as an open-link survey by CCCE (shared across caregiving networks and open to any caregiver). This included 2159 participants in the panel survey and 940 participants in the open-link survey.

[2] A bio-legal family is a group of people that are connected by either genetics or legal systems. This might include biological parents, children, siblings, or any extended blood relatives. Those not connected by consanguinity might become family through legal methods such as marriage, adoption, or fostering. It can also include common-law partners.

providers and other supports in their communities, such as friends and neighbours, often referred to as chosen supports or chosen family (Carton et al., 2010; Cummings et al., 2022; Stajduhar et al., 2020). In a study of 22 homeless participants conducted by Carton et al. (2010), half of the participants identified service providers as their largest source of social support, with several describing them as their only source of support, emphasizing the importance of non-related family support. Therefore, in the absence of bio-legal family members who typically assume these roles, there is a greater need to acknowledge alternative and non-familial support systems. However, these support systems are often not legally recognized and face significant health challenges or limited resources themselves, leading to critical gaps in care for those without other means of support (Stajduhar et al., 2019).

Furthermore, research indicates that the financial stress associated with caregiving is substantial, with over 65% of caregivers reporting financial difficulties in the past year (Canadian Centre for Caregiving Excellence, 2024). Many caregivers experience reduced work hours, lost income, and out-of-pocket expenses for medical supplies, transportation, and other essential care-related costs (Richards et al., 2024). For adults facing housing precarity, these challenges are even more pronounced, creating considerable barriers for those who lack the financial resources to secure additional care. The report further reveals that 41% of caregivers live with their primary care recipient. Conversely, for those who are precariously housed, various policies restrict individuals from cohabitating or enforce guest policies that limit their ability to receive care from informal sources, a challenge that will be explored in greater detail later (Stajduhar et al., 2024). Lastly, the report indicates that emotional support is a critical component

of caregiving, accounting for 69% of care-related duties[3] (Canadian Centre for Caregiving Excellence, 2024). Maintaining well-being, particularly at the end-of-life is often heavily dependent on access to consistent social supports (Canadian Centre for Caregiving Excellence, 2024). However, precariously housed adults frequently experience isolation from their support systems as a result of unstable housing and frequent transitions throughout the housing and healthcare system. These barriers influence not only where care is provided but also how accessible it is.

Part 3: Social Connection

The World Health Organization and others have recently recognized social connection, or lack thereof, as a key social determinant of health and global public health priority (Pivodic et al., 2024; Tinaikar & Scrauben, 2024; World Health Organization, 2024). Although its role and influence on health have previously been overlooked (Pivodic et al., 2024), the relationship between social connection and health is receiving growing attention across various disciplines (Holt-Lunstad, 2022). In its simplest form, social connection can be understood as "when you feel like you belong and have the support and care that you need" (Centre for Disease Control, 2024, p.1). The more general term for social connection is often social support (Wilkinson et al., 2019). Holt-Lunstad (2022) contends that social support is a functional indicator of social connection. Social support heavily relies on feelings of belonging, access to emotional support (Holt-Lunstad, 2022; Wilkinson et al., 2019) and reflects a sense of place within a community or group (Tuan, 1997). For this study, the idea of social connection is defined as a person's perception of meaningful or emotional interactions with others.

[3] I contacted the Canadian Centre for Caregiving Excellence to clarify how this statistic was quantified. It was measured by asking caregivers about the type of care and support they provided to their main care recipient, specifically whether they spent time with them, engaged in conversation, and listened to them.

Social isolation[4] frequently affects adults experiencing homelessness (McCune et al., 2022; Smith et al., 2023). Galabuzi (2016) states that "groups experiencing some form of social exclusion tend to sustain higher health risks and lower health status" (p.388). Furthermore, social isolation has been recognized as both a precipitating and perpetuating factor in adults' experiences of homelessness and housing instability (Smith et al., 2023). In a study by Petrovich and Cronley (2015), semi-structured qualitative interviews with adults experiencing homelessness revealed that while participants identified a range of factors contributing to their housing instability, the loss of social support and subsequent isolation were primary contributors. At the same time, social support plays a crucial role in mitigating these challenges, as individuals experiencing homelessness frequently engage in acts of mutual aid, forming informal networks of care to meet daily needs. These relationships, though often overlooked in policy and research, can provide essential resources such as food, shelter, and emotional support, contributing to resilience in the face of systemic barriers.

As housing policies increasingly regulate visitor access and limit guests in shelters or supportive housing facilities, precariously housed adults often struggle to maintain these vital social connections (Stajduhar et al., 2019). In some cases, these policies further isolate individuals by restricting access to informal support systems that provide companionship, caregiving, and even end-of-life care. Chan et al.'s (2024) study revealed that participants emphasized the necessity of social support when facing the end-of-life, particularly since dying at home is often dependent on the presence of family, friends, or chosen family. Although these

[4] Social isolation is characterized by the interrelated concepts of social disconnection and loneliness stemming from limited contact or meaningful relationships with others, or related perceptions thereof. Older adults may be particularly at risk for social disconnectedness because they are more likely to live alone, experience loss or changes in their social networks (e.g., spouse, family, friends), and have chronic conditions and impairments (e.g., mobility, sensory, cognitive).

supports may not always be formally recognized like bio-legal family members, they frequently provide similar forms of care, including emotional support and assistance with daily tasks (Green et al., 2013). The reliance on informal networks highlights the ways in which people experiencing homelessness help one another, filling critical gaps left by inaccessible formal healthcare systems. By recognizing the role of informal caregiving and social support, it becomes clear that social connection is not only a determinant of health but also a crucial survival strategy for those navigating housing precarity.

3.1 Geographic Transitions

As previously noted, having a stable and safe space is essential for overall well-being and the ability to maintain meaningful social support networks. However, for individuals facing housing instability, maintaining this stability becomes particularly challenging, especially in the context of end-of-life care. Research shows that transitions in care are common at end-of-life (Abraham & Menec, 2016), but for those already experiencing barriers to care, these transitions can be even more frequent and harmful (Guo et al., 2022). Milligan (2016) notes that involuntary relocation is associated with increased morbidity and mortality, highlighting the risks of being displaced from familiar environments. These risks are further amplified for individuals experiencing homelessness, who often navigate multiple transitions between care settings (Guo et al., 2022). In a retrospective cohort study of 61 homeless patients, 75% were transferred to another place of care, with nearly 50% experiencing at least three transitions during the end-of-life phase (van Dongen et al., 2020). These frequent relocations often occur when residents' care needs "become too great" (Stajduhar et al., 2024, p.7), mandating housing staff to evict them and forcing them into institutional settings (Shulman et al., 2018). As Stajduhar et al. (2024) note, "Blanket policies resulted in dire circumstances for many declining and dying people, who were left with no choice but to move into an institutional setting (e.g., hospital) to receive needed care,

amplifying their risk for discrimination and social harms" (p.5). While hospitals or acute medical settings may offer more resources than shelters or other transitional housing situations, relocating people at end-of-life can isolate people from their everyday support systems (McCune et al., 2022). Similarly, Shulman et al. (2018) argues that while hospitals can better serve physical needs, shelters are often the best place to meet people's emotional needs. Ultimately, social supports are immensely important to overall health, and numerous studies have shown that people's health declines significantly faster when they're displaced or disconnected from social and emotional support systems (Cacioppo & Cacioppo, 2014; Holt-Lunstad et al., 2010). However, these support systems, which are crucial to adults' experiencing homelessness, can be severely undermined by organizational policies designed to mitigate risks.

Part 4: Place-Based Barriers to Care and Social Support

4.1 Organizational Risk Mitigation Policies

Although precariously housed adults often rely on informal support systems, they also depend on paid providers to meet both their physical and emotional needs. This reliance is increasingly complicated by organizational risk mitigation policies that impact access to care. Many service providers, recognized as key support figures, are limited in their ability to meet care needs due to risk mitigation policies (Cummings et al., 2022; McCune et al., 2022; Lung et al., 2022; Stajduhar et al., 2024).

Chan et al. (2024) argue that "discrimination imbeds within housing policy to restrict dying persons' access to service, as whole buildings become deemed unsafe for care providers to enter" (p. 349), creating perceived safety risks that limit residents' ability to receive essential care. One example of these restrictions is the implementation of "no-go zones," where healthcare providers are prohibited from entering specific buildings (Stajduhar et al., 2024; Wales et al., 2018). Stajduhar et al. (2024) explain that local healthcare organizations have implemented

worker safety policies prohibiting community care nurses or aides from entering designated "high-risk" environments (p. 5). Reimer-Kirkham et al. (2016) illustrate this dilemma through a case study, noting that a participant was "unable to receive palliative care in his current residence because visitors, support people, and service care providers are not permitted to enter the facility" (p. 302) as a result of safety precautions. This paradox highlights a fundamental contradiction in transitional housing: while it offers shelter, its restrictive policies frequently prevent residents from receiving the care they need. Stajduhar et al. (2018) also found that some individuals had home care services discontinued, even when housed, due to safety concerns about their living conditions. In addition to institutional policies, individual providers may independently refuse to enter certain locations based on their own risk assessments, further limiting access to care (Armstrong et al., 2021; Wales et al., 2018).

These policies not only restrict where care can be provided but also shape the nature of the support available. Organizational guidelines frequently limit the type of assistance staff can offer to prevent burnout, which can unintentionally affect the quality of care. For example, housing staff are typically prohibited from providing medical care due to institutional policies (Webb et al., 2015). Shulman et al. (2018) highlight the challenges of administering medication within shelters, noting that most staff are not trained to do so and are often prohibited by policies. Similarly, MacWilliams (2014) points out that community services are restricted from storing medications on behalf of clients, which housing staff identified as leading to decreased opportunities for adults to remain in shelters or housing facilities, therefore increasing the risk of displacement from their support systems. Risk mitigation strategies also extend to broader housing policies, including abstinence-based requirements, which further limit care options for those in need.

4.2 Abstinence-Based Policies

Current housing options are often limited to facilities that require functional independence and adherence to a sober lifestyle, creating significant barriers to care for many adults (Hutt et al., 2018). Reimer-Kirkham et al. (2016) present a case study in which no smoking and drinking policies prevented a participant's boyfriend from providing care, as he was not permitted in the shelter due to his substance use, which "ultimately prevented her from being with her chosen support person in her final days" (p. 301). The inflexibility and impracticality of abstinence-based policies render care largely inaccessible for many, particularly when these regulations are mandated in institutional settings (Vihvelin et al., 2022). For example, Shulman et al. (2018) further highlight that "behaviours associated with substance misuse pose challenges for hospices and care homes," resulting in limited access for homeless populations (p. 41). As a result, precariously housed adults who use substances, along with their support networks, are frequently excluded from both essential care environments and the places where their social supports reside. Similarly, other institutional regulations can further restrict access to care and support. In particular, guest and visitor policies in emergency shelters and temporary accommodations impose additional barriers, limiting opportunities for social connection and informal caregiving.

4.3 Guest and Visitor Policies

Many adults experiencing housing precarity often reside in emergency shelters or temporary accommodations where strict regulations can impact their autonomy and access to social support and care. While informal supports are essential to the social well-being of many adults, policies that prohibit or limit guest access significantly constrain precariously housed adults' ability to receive care. Throughout the literature, restrictive guest policies are consistently identified as a major obstacle to caregiving (Chan et al., 2023; Funk et al., 2023; Johnson et al.,

2023; Reimer-Kirkham, 2016; Stajduhar et al., 2020; Stajduhar et al., 2024). These policies not only affect physical care but also disrupt emotional support networks, increasing and reinforcing social isolation and instability. For instance, Johnson et al. (2023) highlight how guest policies often restrict the amount of time individuals can spend together, thereby limiting their ability to provide consistent care and emotional support. Similarly, Funk et al. (2023) describe supportive housing for adults as "highly controlled, with few tenancy rights and policies that would not accommodate people dying with palliative care or informal supports" (p. 8). Such restrictive environments diminish residents' autonomy, creating barriers for those who rely on friends and chosen family for care.

In some cases, these policies force adults into even more precarious living situations. Stajduhar et al. (2024) report instances in which no-guest policies left participants with no choice but to move, as they were unable to access the care they needed. Another study by Alaazi et al. (2015) echoed this finding, noting that lack of access to social support as a result of rigid visitor policies caused some to deny housing in favor of maintaining supportive relationships. Even within facilities, residents may be prohibited from entering one another's rooms, further limiting opportunities for connection and support (Jenson et al., 2023). Vivhelin et al. (2022) emphasize that these policies prevent non-traditional family members from caring for loved ones at the end-of-life as access to social support is often contingent on housing arrangements, with informal caregivers rarely acknowledged in policy or legislation (Chan et al., 2024). To illustrate, Stajduhar et al. (2024) describe a case in which two individuals had lived together intermittently throughout their lives. However, due to restrictive housing policies, they were never officially recognized as common-law partners and were, therefore, unable to live together limiting their capacity to provide consistent care for one another. Ultimately, the failure to recognize informal

care networks in policy significantly affects adults' care experiences and their ability to meet essential needs. By controlling who can serve as a chosen support based on the living environment, these policies further marginalize individuals who depend on alternative caregiving structures.

4.4 Stigma in Institutional Settings

Discrimination and stigma in acute and institutionalized settings also impact the quality of care individuals receive, influencing where and how they die, as well as whether their preferences are honoured (Santos Salas et al., 2023). Specifically, Webb's (2021) research suggests those experiencing homelessness fear needing care more than death itself and have a considerable distrust of hospitals and healthcare professionals. Stajduhar (2020) adds to this discussion, citing that those experiencing homelessness avoid seeking care as they do not feel worthy of care or believe they will be "cared for by providers that stigmatize and judge them for a lifetime of hardships that have primarily been beyond their individual control" (p. 90). Experiences of stigma, whether based on perceived or real concerns about treatment, strongly contribute to the fragmented standards of care faced by marginalized populations. Moreover, precariously housed adults living with addiction also report internalizing discrimination experienced in healthcare settings and feeling shameful about their substance use (Hudson et al., 2016; McNeil & Guirguis-Younger, 2012). Cook et al. (2022) further emphasizes that there are significant challenges in providing end-of-life care for those who use drugs or alcohol and that very few studies address evidence-based models of care for this population. Both service providers and precariously housed adults believe marginalized populations are excluded from traditional end-of-life care services due to the stigma and perceptions of illicit drug use and unhoused status (McNeil & Guirguis-Younger, 2012). In a systematic review conducted by Cook et al. (2022), two studies found that stereotypes associated with adults who use substances

contributed to providers deprioritizing their healthcare needs, resulting in their exclusion from mainstream end-of-life care. This stigmatization also impacts their social connections, particularly in institutionalized settings. For example, a scoping review published in 2024 highlights that people experiencing homelessness encounter multiple barriers to housing, income security, and healthcare due to various forms of stigmatization and discrimination. This stigmatization can lead to practices within institutionalized settings that inadvertently restrict their access to necessary support systems, including visitation from friends and family (Canham et al., 2024). Similarly, Hatzenbuencer (2013) argues that discrimination in healthcare settings, particularly when health professionals make judgments about visitors based on stereotypes, can limit people's ability to interact with their support systems. These barriers not only limit access to care but also increase social isolation, which is particularly harmful for precariously housed adults nearing end-of-life.

Part 5: Summary of the Literature

For those experiencing housing precarity, the absence of stable housing introduces unique challenges to accessing palliative care. While existing research highlights the importance of social connections in influencing health and care access, there remains a significant gap in understanding how these connections specifically affect end-of-life care for those without stable housing. This study seeks to fill this gap by examining the role of 'place', including both physical and social aspects, in shaping the care experiences of adults facing housing insecurity at the end-of-life. The findings from this study can inform service delivery and better support for the social needs of individuals facing inequities. The research questions guiding my study are outlined below:

1) How does 'place' shape experiences of care for precariously housed adults nearing end-of-life?

2) What are the subjective meanings and perceptions of home for precariously housed adults nearing end-of-life?
3) How can these understandings be used to deliver end-of-life care that meets the social needs of precariously housed adults?

Methodology

My research draws on data from a larger ethnographic study titled "Caregiving for vulnerable and marginalized older adults at the end-of-life" (CIHR, PJT – 173369). This is a four-year project (October 2021-September 2025) focused on providing a detailed description of caregiving at end-of-life in contexts of inequity across two Canadian cities. Building on this larger project, my research study focused on a subset of data examining the factors that shaped precariously housed adult's experiences of care. The objective of my study is to investigate the role of 'place' in shaping the end-of-life care experiences of adults and to describe the subjective meanings of 'home' from their perspective.

This study employed an ethnographic research design, drawing on observational field notes and interviews guided by combining geographical and health equity lenses. A geographical lens pays attention to the interplay between place, space and care and provides greater insight into the significance of *how* and *where* care is delivered (Power & Hall, 2018). This is particularly important when exploring precariously housed adults' experiences of care and identifying which aspects of care are most important to them. Moreover, this lens can prompt us to consider how care may change the meaning of spaces, such as the home environment and how precariously housed adults identify home (Power & Hall, 2018). Wiles (2024) emphasizes how caring is a situated and relational practice and that care experiences are often shaped by the provision and distribution of resources and available health care services (Wiles, 2024). Milligan (2016) similarly argues that "the availability of formal and informal care across space and between differing social groups is, thus, subject to varying social and political perceptions of rights and responsibilities in the field of caregiving" (p.6). Therefore, this approach provides a framework to help understand how macro and local systems influence places of care, caring interactions and access to chosen social supports (Wiles, 2024).

Health equity adds to this lens by recognizing how systems and structures are patterned to distribute resources and the conditions for good health. This enables us to examine how social, economic, and political systems create inequities in health, often privileging higher socioeconomic groups while disadvantaging those with fewer resources (Nixon, 2019; Reimer-Kirkham et al., 2016). This perspective shifts the focus away from seeing differences in health as a result of genetics or behavior towards the structural factors that limit individual agency and perpetuate marginalization (Nixon, 2019; Stajduhar et al., 2020). However, Nixon (2019) draws our attention to the sometimes problematic framing of health inequity, noting that it is frequently depicted as a problem exclusively impacting "those who are marginalized" (p.2). This outlook tends to prioritize addressing the needs of specific groups rather than targeting the underlying social structures that perpetuate disadvantage (Nixon, 2019). By redirecting our focus to these systemic structures, we can better understand how inequities shape health outcomes. Specifically, this lens helps us examine how inequities in resource distribution and unequal social hierarchies contribute to poorer physical health, emotional well-being, and access to care, especially for precariously housed individuals. Taken together, the combined geographic and health equity lens seeks to investigate how these inequities intersect and impact experiences and places of care, particularly for those who are precariously housed.

Ethnography as a Methodological Approach

Ethnography, as the systematic study and description of peoples, has its roots in the work of German scholars in the eighteenth century, particularly through their involvement in the Russian Empire's exploration of Siberia (Zammito, 2016). Vermeulen (1995) traces the development of ethnography and ethnology, terms coined by German scholars, who framed ethnography as the detailed description of specific peoples and ethnology as the comparative theory of these peoples. These early foundations were further systematized in German

universities, notably at Göttingen, and later translated into Greek terminology to formalize the discipline (Zammito, 2016). However, while ethnography has deep historical origins in German scholarship, this study adopts a methodological framework aligned with the Chicago School of Sociology. The Chicago School, active in the early twentieth century, broadened the application of ethnographic methods to urban social environments, emphasizing the study of social dynamics within urban settings (Deegan et al., 2011). This approach informs my research as I explore the end-of-life care experiences of precariously housed adults through a combined geographic and health equity lens.

Blumer (1969) and Gans (1995) advocated that participant observation was a critical approach to research as they believed other approaches would misrepresent the naturally occurring social life (Wilson & Chaddha, 2009). Blumer argued that social reality is not an objective entity but a product of human interaction and interpretation (Deegan et al., 2001). Similarly, Gans believed that participant observation could reveal the perspectives and experiences of marginalized or understudied groups that might be overlooked in traditional positivist research (Wilson & Chaddha, 2009). He claimed that by giving voice to these groups and understanding their lived experiences, researchers could challenge prevailing stereotypes and offer more nuanced portrayals of their social realities. Critical ethnography employs methods commonly used in conventional ethnography, including long-term field immersion, participation observations and interviews with the aim of interrogating "hegemony, oppression, and asymmetrical power relations in order to foster social change" (Palmer & Caldas, 2015, p.1). Madison (2005) argues that this approach "takes us beneath surface appearances, disrupts the status quo, and unsettles both neutrality and taken-for-granted assumptions by bringing to light the underlying and obscure operations of power and control" (p.5). Through this process, the

researcher contributes to advancing social justice discourses (Madison, 2005), reinforcing the ultimate goal of using knowledge to drive social change (Thomas, 1993) and legitimizing and making visible participants "silenced realities" (Palmer & Caldas, 2015, p.4).

In this study, ethnographic methods (observational field notes and semi-structured interviews) were the main data collection methods for this study. Ethnography's longitudinal nature enabled the observation, documentation, and analysis of participants' experiences as they navigated the health and housing systems. This approach captured critical moments of change, highlighting inequity, stigma, and displacement while documenting moments of resilience and positive experiences. These methods facilitated deeper engagement with participants, supporting a more nuanced understanding of the complex issues they face, and being witness to the inequities, judgements and stigma they experience regularly. Many participants struggle with trust due to past experiences with systems that are supposed to support them, making the formation of trusting relationships a foundational aspect of this work. Ethnography allows for relationships to be built over time through multiple interactions with participants and with their healthcare teams and social supports. This level of engagement also led to more fulsome stories and an understanding of the participant's past histories and care experiences. While reviewing the data and reflecting on the data collection process, several "breakthrough" moments became apparent, where relationships deepened as trust was established through the exchange of shared information. For example, one participant, David, initially hesitated to share details about his upbringing and personal history, attributing his reluctance to memory loss. However, about two months into our conversations, he began to open up after I shared some of my own experiences. When we discussed his earlier hesitation, he mentioned he was able to share his story with me now as he felt safe with me, and explained that I wasn't a "cold one" who "made it all about

work." This trust was further cultivated through mutual vulnerability that aided in diminishing the inherent power imbalances and strayed away from the dynamic of "researcher" and "other" as noted by Palmer and Caldas (2017, p. 5). Furthermore, my efforts to establish connections with participants varied for each individual, while the ability to assess their desired level of engagement was essential to the process of relationship building.

Positionality

Moreover, a key element of ethnography is its concern with positionality and reflexivity (Hammersley & Atkinson, 2019). Reflexivity encourages us to acknowledge our own power, social location, and biases and how these aspects of our identity influence the representation and interpretation of the data (Madison, 2005). Fundamental to a reflexive approach, particularly when engaging with more vulnerable communities, is maintaining transparency throughout the research process by acknowledging reasons for engagement and explicitly articulating one's positionality to participants. A growing number of researchers have encouraged ethnographers to "embrace vulnerability through self-reflexivity of their own positionality in dialogue with participants" (Palmer & Caldas, 2015, p.5). Going into the field, I recognize the identities I bring into this work and how I may be perceived by communities that I don't have similar experiences with. I have the unearned advantage of many parts of my identity being in alignment with broad social norms (able-bodied, heterosexual, white, female). I did not ask for these benefits, but I receive them all the same. A strategy I employed to discuss biases and challenging feelings that I was confronted with was through my reflexive field notes, as well as through regular debriefs with a Ph. D candidate and project coordinator, (AM). Through these debriefs, (AM) would prompt me to deeply reflect on why I was feeling certain ways and how to use those feelings as a learning opportunity to be a better researcher and to reflect that in my work. Nixon (2019) argues that developing the capacity to recognize privilege requires both learning and relearning.

However, throughout my education the process of relearning has rarely been discussed or considered. This year, a significant aspect of my personal growth has been reflecting on the meaning of privilege, recognizing unearned advantages, and actively relearning the many ways in which I have been taught. In their article, Nixon (2019) employs the example of a gorilla, drawing on the famous psychological experiment by Simons and Chabris (1999), where participants fail to notice a person in a gorilla suit because they are focused on another task. Nixon uses this metaphor to highlight how privilege and systemic inequities can exist in plain sight yet remain unseen due to dominant perspectives or negligence of one's own privilege. They explain that "learning to see the gorilla is a strategy for becoming less oblivious and less harmful" (Nixon, 2019, p. 5). Over the past year, I have made a concerted effort to apply this concept, striving to "see the gorilla" in every space I occupy. Beyond simply reflecting on my positionality, I actively made decisions in my approach aimed at minimizing harm and addressing power imbalances. This involved being intentional about my communication style, prioritizing the use of accessible language, openly sharing my own vulnerabilities, and paying close attention to my appearance, including thoughtful choices around clothing and accessories. For example, I often wore casual black clothing and sneakers, and I rarely wore jewellery or accessories. Moreover, I approached each interaction without assuming trust would be granted to me. Instead, I prioritized earning trust gradually, fostering relationships over time without imposing expectations on those I worked with. I engaged with participants without adhering to a predetermined research agenda, allowing conversations to unfold organically, keeping the dialogue open and giving space to participants to share what they felt comfortable with. I additionally refrained from recording our interactions until I felt I had earned the participant's trust, again, focusing on building genuine relationships rather than prioritizing data collection.

This project has profoundly influenced my perspective, shaped my politics and taught me the importance of listening more and speaking less. It has encouraged me to engage with discomfort, anger, and naivete in meaningful ways. My goal in this research is not to uncover absolute truths but to listen and learn. I feel deeply fortunate to have been welcomed into people's homes and entrusted with their stories, histories, and experiences.

Methods: Participants, Recruitment and Data Collection

This subset of data consisted of three participant groups: (1) adults experiencing housing precarity who had a palliative diagnosis, (2) their identified support person, and (3) health and social care providers involved in providing care to precariously housed adults.

Recruitment

Initially, the larger research team collaborated with equity-focused mobile palliative care teams from each Canadian city who were able to highlight caregiving challenges being experienced by the clients that they supported. Several meetings were conducted prior to my data collection to refine the study's objectives and procedures and ensure they reflected the priorities and needs of the communities they worked with. After gaining ethics approval (See Appendix A) from two research ethics boards (H22-00313 for BC; HREBA CHC-22-0032 for AB), our team proceeded with data collection.

Interviews across two provinces with equity-oriented mobile palliative care team members began in August 2022. The participants included a range of professionals such as physicians, nurses, psychiatrists and outreach workers. The interviews explored their daily roles and interactions with clients, the informal supports available, the dynamics between clients and their caregivers and strategies for supporting caregivers. Data collectors expanded their involvement in April 2023 after gaining consent (See Appendix B) by attending clinical rounds

where individual client cases were discussed. After several months of observing clinical rounds, data collectors began shadowing members of the mobile teams and accompanying them during client visits in various settings such as shelters, transitional housing facilities and hospitals.

Although the larger study focuses on two Canadian cities, my study draws exclusively on data collected in British Columbia, and the following sections will specifically outline how data in British Columbia was collected and analyzed. The data collected for this analysis took place over 12 months, from September 2023 to September 2024. Observations (n=75 hours) and interviews (n=10) were conducted by myself and a Ph. D candidate (AB) who was also a research assistant on the primary study.

In British Columbia, our research team collaborated with The Palliative Outreach Resource Team (PORT) operating out of Victoria. The team is a combined partnership between the University of Victoria, Island Health, and Victoria Cool Aid Society. It began as an informal collaboration in 2011 to improve access to palliative care for people nearing end-of-life and experiencing homelessness (Healthcare Excellence Canada, 2023). The team provides a bridge to care for those experiencing barriers to mainstream healthcare access and who are additionally living with serious illness. It is comprised of two physicians (one primary care and one palliative care physician, and a palliative care psychiatrist), two nurses, and two social workers who deliver palliative care to those precariously housed in the inner-city community.

I (AS) began attending clinical rounds held by PORT in early January 2024. The rounds lasted 1-2 hours and were held over Zoom. The information discussed in the rounds was documented in field notes, where initial understandings of the landscape of the work, roles, and barriers to care were collected. I next began shadowing the PORT team in late January 2024. Bi-monthly meetings were held with the larger research team at this time to discuss potential study

participants and initial themes that were emerging. The PORT team facilitated connections between researchers (AS, AB) and participants by identifying clients who had an identified support person, with the client's consent. These connections were made in person during observational visits with PORT, or PORT would provide clients with the researcher's contact information (See Appendix C). I most often accompanied the outreach worker, who would ask permission from the client before introducing me, and explaining my association with the university and the study. Once introduced, I obtained both observational and interview consent from clients and focused on building relationships (See Appendix D and E). As my relationships developed, I sought permission to engage with their identified support person. Depending on the client's comfort level, meetings with their identified support person were held together with the client or separately. Each client and their identified support person received a $50 cash honorarium per visit, regardless of the duration of the visit. Due to the nature of the work, sometimes locating participants was challenging as phones are frequently lost and means of communication are constantly changing. Fluctuating health status also proved difficult, as some participants were in and out of the hospital and lived relatively transient lives. The mobile team was particularly helpful in providing health updates about clients and passing along changed phone numbers to keep in contact with participants.

Observations with participants and their support person were conducted on average every 3 weeks between September 2023- September 2024 and anywhere between 1-2 hours. Observations occurred in shelters, hospitals, hospice units, transitional housing facilities, long-term care facilities, cars, and outdoor spaces during all times of the daytime hours. Communication also included texts and phone calls, all documented in detailed field notes (See Appendix F for template). My observational field notes focused on capturing information about

the environment, interactions, and activities, which were always followed by a reflective overview of the experience. Observations were also audio recorded with the participant's permission to document quotes verbatim. Ongoing verbal consent was obtained during every observation to ensure participants could withdraw at any time without impacting them or their continued care.

Service providers involved in the client's care were also recruited to partake in interviews during this time. This happened in a variety of ways. For example, some providers were identified during clinical rounds as being additionally supportive to certain participants. With the client's consent, members of the PORT team would introduce us to these providers, where we could share information about the study and invite them to participate if they were interested. Another way that service providers were approached was if they were introduced to us during a client visit. For instance, during observational visits, some clients would have members of other teams come in to provide them with different care tasks. Again, with the client's permission, researchers would ask if they would be interested in participating in the study and then obtain consent from the service provider (See Appendix G). Seven semi-structured interviews with service providers were conducted by AS (See Appendix H for interview guide). The shortest being 35 minutes and the longest being 1 hour and 29 minutes. The smaller number of interviews aligns with the study's methodology, which emphasizes capturing in-depth understandings rather than a generalized perspective. Each of the service providers interviewed was a member of their respective housing or medical teams and had intimate knowledge of the participants we engaged with. Demographic data of service providers was collected during the interview process (Table 1), whereas no direct demographic data was asked of precariously housed adults or their identified supports and was instead collected through ongoing conversations after trust was

established. Exiting the field occurred after thorough discussions with the research team or in the case of a participant's death.

Table 1: Service Provider Demographics

Participant	*Age*	*Gender*	*Ethnicity*	*Highest Level of Education*	*Professional Role*	*Years in Current Position*	*Hours a Week on Average Worked*	*Formal Palliative Care Training*
1	34	Male	Biracial	Bachelor's degree	Front line housing supervisor	1 year	40	No
2	62	Male	Caucasian	Some university, no degree	Housing support worker	4 years	35	No
3	32	Female	Caucasian	Bachelor's degree	Clinical nurse leader	3 years	50	No
4	69	Female	Caucasian	Bachelor's degree	Housing Support worker	3 years	35-40	Yes
5	32	Female	Caucasian	Some college, no degree	Mental health worker	4 years	36	No
6	43	Female	Caucasian	Bachelor's degree	Outreach worker	4 years	10 +	No
7	25	Female	Caucasian	Bachelor's degree	Outreach worker	1 year	32	No

Analysis

For the purposes of this analysis, I employed a case report approach (Schwandt & Gates, 2018) using reflexive thematic analysis (Braun & Clarke, 2021). This involved consolidating observational and interview data into three case reports, which were then analyzed for recurring themes. The overarching theme, how place shapes experiences of care, was illustrated through narrative synthesis, presenting each case as a distinct story while drawing connections across the cases.

Data collection and analysis were conducted simultaneously to identify gaps while continually adding to participants' stories, which also facilitated a more responsive and iterative approach by working in tandem. This process ensured well-grounded and thoughtful follow-up observations and interviews with participants and their selected supports. Additionally, this approach provided an opportunity to check in with participants throughout the data collection process, ensuring their experiences were accurately captured and understood. This aligns with the reflexive nature of ethnography, as described by O'Reilly (2012), where researchers engage in participant observation and active listening, constantly reflecting on what is being communicated and how researcher bias or power dynamics might influence or misinterpret the data. Maintaining the authenticity of these narratives and honouring them is crucial to the integrity of the data, and this principle was a central point of discussion amongst our research team.

This naturally led to a case report approach as more data were collected over time, allowing a story to unfold. It was well suited for analysis as it often draws on participant observation and in-depth interviews to "understand the experiences, perspectives and worldviews of people in a particular set of circumstances" (Schwant & Gates, 2018, p.346). Schwandt & Gates (2018) assert that case studies "give voice to people who are marginalized, disadvantaged, excluded or vulnerable" (p.346). The case study approach was also a beneficial analytical tool as each participant had different life courses and deserved to have their stories represented individually. Analysis began by compiling field notes from both clinical rounds and field observations and interviews with service providers to create one large document of each case ordered chronologically. These case studies were then read multiple times to ensure a deep understanding of each story and its intricacies. After reading all three cases, it was apparent that

the concept of place played a significant role in shaping adults' experiences of care. From there, the case studies were written to create a narrative of participants' transitions through the health and housing systems, emphasizing place-based barriers and facilitators to their care experiences. Essentially, each case study highlights a different experience, but all three fit under the dominant theme of place shaping experiences of care.

In addition, after the case studies had been compiled and written out, I read back through every service provider interview and observational fieldnote to thematically analyze any additional themes. This prompted me to include an additional results section, as I believed other essential themes had not been entirely captured in the case studies. These initial themes started broad. For example, "home," "transitions," "social connection," and "pathways forward." As I sat with the data, re-reading interviews and field notes and discussions with my supervisors led to more refined themes, such as "home as social connection," "social connection as care," among other themes.

The next chapter, illustrating the core findings of my thesis research, is a planned submission to *The Journal of Health and Social Care in the Community.*

Chapter 2: "Care is Connection": How Place Shapes Experiences of Care for Precariously Housed Older Adults Nearing End-of-Life

Abstract

Most Canadians would prefer to die outside of a hospital setting, "at home," in a familiar setting, surrounded by family, friends, or community. However, the notion of home and its significance as a place for care is a challenging concept for those precariously housed and additionally nearing end-of-life. These intersecting vulnerabilities can lead to more frequent care transitions for older adults, who may be relocated to settings that meet their physical needs but, in the process, are displaced from their communities and disconnected from essential social supports. In this context, the role of place becomes crucial to investigate, particularly how it shapes experiences of care for older adults. Drawing on observational fieldnotes and qualitative interviews, we explore how place shapes experiences of care for precariously housed older adults who are also nearing end-of-life using a combined geographic and healthy equity lens. Our findings reveal substantial barriers as well as facilitators for improving care transitions across various settings. We conclude that advocating for the delivery of services in places of their own choosing and ensuring that adults have access to their social and community supports can facilitate more equitable end-of-life care experiences.

Introduction

Most Canadians would prefer to die outside of a hospital setting (Park et al., 2024). The Canadian Institute for Health Information's latest 2023 report indicated that only 13% of Canadians who died in 2021-2022 received palliative care at home. While this reflects an improvement from the 7% reported in 2016-2017, significant service gaps remain, particularly for older adults who are precariously housed (CIHI, 2023). The Framework on Palliative Care in Canada – Five years Later: A Report on the State of Palliative Care in Canada, acknowledges

these disparities, noting that, “people who may not have resources and supports or whose “home” may not be safe face additional barriers in accessing palliative care. This includes people who lack adequate shelter or who may not have family or friend care providers” (Government of Canada, 2023, p. 4).

The concept of home symbolizes a multifaceted landscape wherein diverse political, physical, emotional, social, and cultural influences converge, shaping experiences of care (Stajduhar et al., 2024). The notion of place is similarly complex. Importantly, place can be understood in multiple ways and is not limited to the built or physical environment. It includes an individual’s sense of belonging or connection within a space or community, reflecting their emotional and social ties to that place (Cloutier et al., 2015; Tuan, 1997). In this paper, place does not have a singular definition but instead reflects a nuanced understanding shaped by various contextual factors.

A key finding from various studies is that adults experiencing housing precarity prefer to remain in a familiar environment, such as a hostel, shelter, or residence, rather than being transferred to a hospital during their end-of-life care, reiterating the importance of sense of place for those precariously housed (Cook et al., 2022; Hudson et al., 2016; Vihvelin et al., 2022). While these environments may not have the same medical resources as hospitals, they are seen as more desirable places for adults to die, as they are perceived as being part of their home and community (Hudson et al., 2016; Stajduhar et al., 2024).

Research by French, Keegan, Anestis and Preston (2021) suggests that adults who face barriers to healthcare, including those facing housing precarity, are more likely to experience fragmented care, leading to multiple care transitions. Transitions in care refer to the movement people make between health care practitioners and settings as their condition and care needs change during the course of a chronic or acute illness (Coleman & Boult, 2003). The Canadian Institute for Health

Research highlights that gaps in care transitions can make adults more susceptible to fragmentation in care, delayed treatment, poor quality of care, negative experiences, compromised patient safety, and adverse medical events (CIHR, 2023). Further research reveals how traumatizing care transitions can be, particularly for the "most vulnerable people with advanced illness who are experiencing these transitions often close to the end of their lives; whose voice is less often heard" (Guo et al., 2022, p. 126). Similarly, other studies indicate that marginalized populations are also more likely to be hospitalized at end-of-life rather than having coordinated, continuous care, which additionally contributes to disruptive transitions (Liu et al., 2024). These transitions similarly contribute to increased isolation and disrupted social networks which has known adverse health consequences.

While there is existing literature on care transitions for older adults, this literature largely focuses on people who are housed, experience financial stability, and most often have family to support them (Stajduhar et al., 2018). Much less is known about the importance of end-of-life care transitions for precariously housed populations. Therefore, this study sheds light on how care transitions impact precariously housed older adults and offers insights into how place shapes experiences of care, which can help inform the creation of policies that promote more equitable access to end-of-life care.

Methodology

Mobile Palliative Care Team

In this qualitative research, we present three in-depth case reports of participants who were receiving support from a mobile palliative care team in British Columbia, Canada. The team is a combined partnership between the University of Victoria, Island Health, and Victoria Cool Aid Society. It began as an informal collaboration in 2011 to improve access to palliative care for

people nearing end-of-life and experiencing homelessness (Healthcare Excellence Canada, 2023). The team provides a bridge to care for those experiencing barriers to mainstream healthcare access and who are additionally living with serious illness. It is comprised of two physicians (one primary care and one palliative care physician, and a palliative care psychiatrist), two nurses, and two social workers who deliver palliative care to those precariously housed in the inner-city community.

Theoretical Framing

We used a combined geographic and healthy equity lens to examine how multiple forms of disadvantage (e.g., homelessness, substance use, gender, race, poverty) shape experiences of care during transitions in care. We aimed to identify patterns related to care fragmentation, difficulties in maintaining continuity of care and challenges in transitioning between housing settings and care teams. These lenses also aided in our understanding of how compounding spatial, social and structural barriers influenced adults' ability to access necessary services, including their community and social supports.

Design

These cases draw on data from a larger ethnographic study titled, *Caregiving for Vulnerable and Marginalized Older Adults at the End-of-life* (CIHR, PJT – 173369). As an extension of the broader project, our study focused on a specific subset of data, examining care transitions for older adults and the factors that shaped their care experiences. We employed an ethnographic research design, drawing on observational field notes and interviews. From August 2022 to December 2024, we conducted over 270 hours of observations alongside 41 interviews with service providers, key informants, clients, their chosen supports, and members of equity-oriented palliative care teams.

Setting

While the larger parent study took place in two mid-sized cities in British Columbia and Alberta, Canada, this paper focuses on three cases featuring data exclusively collected in British Columbia. Observations and interviews were conducted in shelters, transitional housing facilities, long-term care facilities, hospitals, hospice units, and outdoor spaces.

Sampling and Recruitment

This subset of data consisted of three participant groups: (1) adults experiencing housing precarity who had a palliative diagnosis, (2) their identified support person, and (3) health and social providers involved in providing care to precariously housed adults. Initially, members of equity-oriented palliative care teams working in the inner-city were recruited who were able to help identify potential participants experiencing housing precarity and who had received a palliative diagnosis. Their identified supports were invited to participate after if they wished to do so.

Data Collection

For the three cases, repeated participant observations were undertaken, along with their identified support person (n=3). These interviews took place over 12 months, resulting in approximately 75 hours of observational fieldwork for the three cases. Interviews with service providers (n=7) were conducted by the same researcher who conducted observations with the precariously housed adults and their supports to gain a more fulsome and consistent understanding of participants' health status and movement through the health and housing system. In addition, we focused on data from seven interviews with service providers directly involved with the three clients featured in our case reports, as these providers were uniquely positioned to offer detailed insights into how the clients' care experiences were shaped by the various places in which they received support. All interviews were digitally recorded and transcribed verbatim.

Data Analysis

In our analysis, we employed a case report approach to explore older adults' care experiences. This method allowed us to examine the contexts of each participant's situation, providing detailed narratives that illuminate the complexities of their experiences. Each case report is unique, and rather than categorizing them as positive or negative, our aim is to highlight how diverse care transitions are and how they can be better supported, particularly in contexts of inequity.

This assisted us in identifying key patterns and themes that emerged from the participants' stories, drawing connections between their experiences and the broader social and environmental factors at play while also honouring their individual experiences. Data collection and analysis took place concurrently. The larger research team was frequently consulted throughout the analytic process to ensure consistency and rigour of the findings.

Ethical Considerations

Ethics approval was obtained by the UVIC/UBC/VIHA Joint Research Ethics-Sub Committee (Number: BC22-0118) on February 2nd, 2023. Written consent was obtained from all participants, with ongoing verbal consent during the data collection process. Pseudonyms have been used to ensure participant anonymity.

Findings

The findings include three case reports to demonstrate how changes in the physical environment affected participants' care experiences and social connections.

Todd and Maureen

In October 2023, Todd, a 71-year-old white male, was living in a single occupancy room in a transitional housing facility located in an inner-city community. He was estranged from his

bio-legal[5] family but had a constellation of other social supports, including his wife, Maureen, who lived separately in market housing. Todd was living with a number of co-morbidities, including cancer, a long-standing history of multiple hip fractures, and a severe head injury resulting in both physical and cognitive disabilities. He had limited mobility and relied on a motorized wheelchair for ambulation. As a result of his physical disability and lifelong trauma, he used substances (i.e. inhaled street drugs and alcohol) to meet his total pain needs (i.e. physical and emotional). He had an outgoing and gregarious personality, with many friends in the building and in the surrounding inner-city community.

Todd and Maureen had a complicated personal history that restricted them from living together, including domestic violence allegations. In addition, Maureen was also experiencing personal health problems and structural barriers (i.e. poverty, lower literacy, lack of transportation) that limited her ability to care for Todd in her home. Despite these barriers, Todd described Maureen as his main source of emotional support, referring to her as his "home" and "whole world." She frequently visited the transitional housing facility where he lived.

In addition to the support he received from Maureen, he was connected with a mobile palliative care team that served as his primary medical support. He frequently referred to them as "real-life angels." They provided him with outreach services, including transportation to medical and bank appointments, nursing and medical care, and clothing and food support.

In late February 2024, he was transferred to a specialized unit (for people who use substances) at a long-term care facility outside of the inner-city core. Initially, the transition seemed like a welcomed opportunity, as his care needs had surpassed what the transitional housing facility could provide. However, his situation changed considerably over the next few

[5] See Footnote 2 for bio-legal family reference (p.16).

months. In early March, less than two weeks after the transfer, the first signs of new challenges emerged, particularly concerning his pain management and issues arising from having his care team change which signified a loss of known relationships. By April, he reported feelings of isolation, loneliness, and withdrawal. During an interview with a staff member at the facility involved in his care, they noted, “those people [clients on the special unit] just, just hate, hate being here so much because they just feel like they’re trapped because they can’t get out to their community.” They also provided insight into how people’s social supports are often compromised when they are uprooted and relocated, stating, “if you’re in supportive housing, they have a lot of community in those supportive housing sites and even downtown. Again, like, here, it’s kind of structured. And it's challenging for them to feel like they can have company over.” She added, “like, they do have, they do have a lot of close friends and family in the community. They just physically can’t get to them,” highlighting a combination of mobility-related issues that further isolated people from their social supports in a geographic sense.

In early May, he expressed his deep dissatisfaction with the long-term care facility he was in, stating that he “hate[d] it”, wanted to return to the transitional housing facility, and was struggling with withdrawal. He also emphasized how much he missed his friends and said he was “completely segregated.” He described his transition through the system as a “springboard” and reiterated feeling “cut off from the world.” He also shared that his wife had started visiting less often due to the stigma she was experiencing from staff.

In late May, his wife was banned from the long-term care facility due to behavioural issues deemed inappropriate for the care setting, forcing them to meet outside on a bench located off the property. This created considerable distress for them both, Todd noted “they’re taking something very special from us.” He believed that the staff “wanted him to die all alone.”

Additionally, Todd had no means of contacting her besides using the phone at the nurses' station at the facility and he often complained about having limited privacy during their phone calls. The restrictions on her visitations were still being upheld in June, and consequently, they both continued to discuss how emotionally damaging this had been for them.

Todd was moved to another unit within the facility in July, where staff believed they could monitor him more, as there were discussions of him being evicted due to increased drug use. He was still living there in August, but his relationship with Maureen was fractured. In September, the team learned he had self-discharged himself from the facility as a result of the restrictive policies and was living with Maureen but had not been able to follow up since.

This case exemplifies the extent to which institutional policies affected his social connection with his spouse, ultimately leading him to discharge himself back to his community. In being displaced from his previous residence, the connections with his wife, friends, care team and source of drug supply were damaged. As a result, he experienced withdrawal, social isolation and broken trust. Research has shown that people's social supports are vital in their provision of care. Stajduhar et al.'s (2024) work highlights "how people discriminated by and excluded from mainstream society meet their own health and social needs by forming communities of care and support" (p. 2). Participants in our study were often relocated to new environments where different levels of care were provided. For many of our participants, who have faced ongoing stigma and discrimination in institutionalized environments, this can be exceptionally traumatic, particularly when they're displaced from their community and the people who support them. However, in some instances, these settings can also facilitate and strengthen connections, as shown in the next case study with Matthew and Brock.

Matthew and Brock

Matthew, a 69-year-old white male, had been a patient in the hospital when he was referred to the mobile palliative care team in September 2023 following his diagnosis of rectal cancer. Before being admitted he was living in his truck. A health provider described him as being quite social before his diagnosis and emphasized his dislike for spending time alone. He was well-connected to a local harm reduction organization, often referring to them as "his community." While in the hospital, the mobile team was in the process of arranging alternative housing for him, as he was no longer able to live in his truck due to his increased medical needs.

However, in October, before his new housing was finalized, he self-discharged himself and was living at a friend's house with Brock, his ex-partner and his main source of support, who he referred to as a "godsend." At this time, Brock played a large role in attending to his care needs and providing emotional support. Brock described Matthew as happy-go-lucky and an all-around good person who loved to tell stories, even made-up stories, to keep everybody happy. After his self-discharge, the mobile team had a difficult time locating Matthew and was worried about his potentially declining health status due to his recent diagnosis. Through communication with the local harm reduction organization, they were able to locate him and offer him a room at a shelter in the inner-city. Initially, he was hesitant as he was concerned about the environment at the shelter, but eventually he decided to accept the offer. Unfortunately, the shelter's strict no-visitor policy left Matthew feeling increasingly isolated. It was identified in a fieldnote that due to the restrictive visitor rules, he could no longer spend time with his "main support person," leaving him "all alone in his room."

When asked if Brock was able to visit the shelter, Brock recalled, “No, that was one thing they would not let me do. As much as we pushed for that. And the [mobile] team also, they were amazing. They tried everything to get them to allow me to be there for him. But what ended up, I was staying at the [hotel] at the time. So, he always came over to the (hotel), he spent more time at my place at the [hotel] than he did at [shelter] because, he did not want to be alone.” A service provider directly involved in Matthew’s care added, “And we move him, we get him housing in this place where he’s not allowed any visitors. Like, this was a huge detriment to his health, because he was so afraid to be alone. He was so afraid of dying alone. He was so afraid of being alone, so afraid of falling, afraid of something happening when he was alone. So, it was like he was in a constant state of anxiety in this space that was supposed to be his home. And, and I guess that’s just an example of how there’s sometimes people who move into these places whose policies stop them from getting care.”

In addition, homecare service providers expressed hesitation in providing care for Matthew at the shelter as they were worried about their safety. It was noted that his pain was not being well managed because he couldn’t get access and was purchasing drugs ‘downstairs’ in order to meet his total pain needs.

In December, after being attacked by a dog at the shelter, Matthew was sent back to the hospital, where he was transferred to hospice. Again, Brock voiced that Matthew was apprehensive about hospice and felt unsure about how he was going to adjust. However, hospice provided a better place for Matthew as Brock was allowed to spend nights there and come and go freely. The mobile team continued to be involved, visiting him, checking in and trying to ensure he had his needs met as best they could. In early February, Matthew died in hospice surrounded by Brock, their close friend Kyle, and members of the mobile palliative care team.

Reflecting on their hospice experience, Brock shared, “I would recommend it for anybody. They were the most wonderful, friendly, supportive, helpful, caring… I could stay, you know, it was, there was no limitations on visits or anything…The friends he did have in town here, everybody came to visit him, everybody, you know, came up and spent time with him.”

The service provider also reflected on this experience, sharing that, “Matthew was dying in hospice and Brock slept there most nights and hospice fed Brock too…But it, that was beautiful. Like it really was, and I, I think hospice is different because people really get to have their own space. And for people that we work with, that’s huge. Like getting to have this space that feels secure where they know they’re not going to be kicked out the next day.” Brock was also provided with grief support from the mobile team after Matthew’s passing.

This case highlights the influence of place of care experiences for Matthew, both positively and negatively. While the shelter’s restrictive policies isolated him from his support system, the hospice setting allowed him to be surrounded by his identified supports. This case also underscores the importance of care continuity, not just for patients, but also for their support systems. Brock felt supported not only by the hospice staff but also by the mobile palliative care team. This illustrates the trust built with the team and emphasizes the value of maintaining consistent care teams across transitions, particularly in end-of-life care. While transitions often reflect the need for specialized care, they can be challenging for adults who have little trust in the medical system. For Matthew, the continuity of care he experienced was instrumental in enhancing his emotional well-being and quality of life at the end of his life. Research has identified barriers that exist to receiving care in transitional or shelter housing facilities. Namely, restrictive guest policies and “no go” zones that prohibit people from accessing their community supports, including medical staff. Medical evictions are also becoming more frequent, where

housing facilities evict people on the basis of their medical needs surpassing what the facility can provide. Therefore, hospitals or institutionalized settings such as long-term care or hospice environments often become the default setting. However, a growing body of research has expanded our understanding of the factors that may shape preferences for dying in institutional settings rather than at home, including socioeconomic factors such as poverty and housing insecurity (Funk et al., 2022). Additionally, some institutionalized settings can provide relief from community and the hardships of living in supportive or transitional housing settings if they cannot receive proper pain management or experience worsening health conditions (Funk et al., 2022). This next case report shows pathways to improving transitions in care for precariously housed adults.

Ron and David

Ron was a 60-year-old white male living in supportive housing a few blocks from the inner-city core. He had multiple intersecting health challenges, including chronic obstructive pulmonary disease (COPD), alcohol use disorder, and fibrosis. Estranged from his biological family, Ron had grown up in an adoptive family, which he described as physically and emotionally abusive.

For his care, Ron was connected with the mobile palliative care team and another local team that assisted with his medical and housekeeping needs, including cleaning, food, clothing support, and ongoing maintenance of his frequently broken electric scooter, which was his main form of mobility.

Trusting others was difficult for Ron, and he relied heavily on another resident, David, as his primary support. They described their relationship humorously as a “husband and wife” dynamic, often bickering about who played the wife role, yet mutually supporting each other.

Both consumed between 13-15 beers a day and could almost always be found together in Ron's room, watching TV. Even though David lived across the hall, Ron kept an open-door policy, explaining that it was easier for them to see each other that way. Their relationship, though centred around shared alcohol use, also involved mutual care: they fed, clothed, and looked out for each other. Ron, for example, often encouraged David to wear a helmet to protect himself from his frequent falls. Ron also shared that he thought the idea of home was "being able to talk to at least one person who understands you." He explained that person for him was David, exemplifying how much they relied on each other in the absence of bio-legal family and highlighting that "home" was not just a physical place but was defined as much by the people who surrounded and supported him and proximity to his main support.

In late April, David entered detox. Ron became increasingly lonely and isolated, refusing to engage with other residents to meet his emotional needs at this time. Additionally, he had to ask people he didn't necessarily trust in the building to help him meet his alcohol use needs.

In late May, when David returned to the housing facility Ron had been moved to a room downstairs to accommodate his increasing mobility needs. Although Ron and David were still living in the same facility, David shared that it felt like he had to "walk down the block" to see Ron.

Soon after, it was announced that David would be transferred to another housing facility, 20 minutes away, due to his increasing care needs related to incontinence. Ron became progressively anxious about what he would do in David's absence. The housing worker echoed this response, citing that there is no "mechanism in place for transferring someone... to more adequate housing that is not traumatizing to people."

In early October, David was moved. They both communicated a considerable amount of distress; Ron shared that it "fucking sucks. I miss him already. I thought I was supposed to go too, but I guess I have to wait longer or something, I don't know. If even one of us had money, the other would be moving with the other, but we don't have the jingles for that." The mobile palliative care team was aware of their reliance on each other for support, and Ron was put on a waitlist for the same housing facility to keep them together.

The relocation of a social support caused panic and worry for both Ron and David. This case also serves as an example of how important it is to try to facilitate better transitions in care for people who have identified support systems and how to assist in less stressful and harmful transitions at end-of-life.

The stories of Todd, Matthew and Ron and their identified support persons reveal barriers but also highlight areas where elements of care transitions were successful. Despite each participant's unique circumstances, the concept of place played a crucial role in shaping their experiences of care. To illustrate, many older adults facing housing precarity often find themselves estranged from their bio-legal families and depend on their communities, chosen families, friends, or health and social service providers to meet their care needs. What emerged as particularly significant in this study was the critical role of these support systems and how transitions in their care influenced their access to their identified support systems. According to Reimer-Kirkham et al. (2016), the World Health Organization's definition of palliative care "recognizes that physical and mental suffering is complexly interrelated and capable of influencing the other" (p. 294). However, in all three stories, the emotional and mental health of clients seemed to be an afterthought from the care system perspective.

Discussion: How Place Shapes Connections to Community and Social Supports

Collectively, the findings presented in this thesis demonstrate the various ways in which the concept of place can be understood and seen to influence caring relationships for those who are marginalized at end-of-life. Furthermore, they affirm that place does not hold a singular meaning or capture a single experience; rather, it is constructed in relation to lived experiences and influenced by power dynamics. Participants' care experiences were shaped primarily by their access to social connections, which were often influenced by their living environment. This demonstrates how power shapes social spaces such as the home and consequently affects the relationships and social connections within these settings.

On a system level, Wiles (2024) encourages us to critically examine how care is influenced by broader forces that shape the availability and distribution of resources and services. They contend that macro-level factors, such as health policies and economic systems, interact with more localized contexts to influence everyday experiences of care. Wiles's (2024) most recent work describes care landscapes as dynamic and shaped by the availability, flow, and distribution of care policies, workforces and practices at different scales including local, regional, and global. They also discuss the variety of settings in which care occurs, including institutional, domestic, and community spaces including both the physical and built environments. They state that over time, these care arrangements can transition due to any of the various factors mentioned above and reshape the place where care happens and the people involved (Wiles, 2024).

A health equity lens highlights the intersecting social and structural forces that limit decision-making, shape available choices, and constrain options, ultimately exposing adults to increased harm especially at end-of-life (Stajduhar et al., 2024). For participants experiencing multiple vulnerabilities, their autonomy and ability to advocate for themselves were significantly reduced.

Additionally, policies and place-based barriers further restricted their access to care, particularly their connections to community and chosen support systems, which this paper underscores as critical to their well-being.

Considering these challenges, it is crucial to provide precariously housed populations with opportunities to receive care in settings they identify as safe and supportive, whether in more institutionalized settings or community spaces alongside their identified support systems.

Chapter 3: Expanding the Notion of Home: Social Connection, Barriers, and Pathways Forward

These findings also address the second research question in greater detail, which explores the meanings of home for adults facing housing precarity. Although the case reports focused on data collected from three participants, this additional finding chapter incorporates insights from two more participants and three additional service providers. In total, this section is based on observational data from five participants, their identified supports, and ten interviews with service providers. Through thematic analysis, three key themes emerged: (1) home as social connection with the related sub-theme of social connection as care, (2) care transitions and place-based barriers to social connection, and (3) pathways forward for strengthening social connection.

All participants and their chosen supports were precariously housed, residing in various settings such as transitional housing, emergency shelters, unsheltered locations, supportive housing, and low-income housing. Over the course of the study, some participants also spent time in long-term care facilities, hospitals, and hospices. Three of the five participants were actively using substances, and two had physical disabilities that required the use of a wheelchair for mobility. Participants ranged in age from 50 to 72, with all five identifying as white males. Among their chosen supports, one was a female, one was an Indigenous male, with the remaining supports being white males. This demographic profile aligns with previous studies by Stajduhar, which have identified white males as one of the groups that are most in need of additional support.

"Home" as Social Connection

Given that housing is one of the most significant determinants of health and that most people prefer to be at home during their end-of-life experiences, it was important to ask how

participants defined home. While home is typically associated with being a therapeutic, clean, warm, safe space, and connected to the necessary resources for end-of-life care, it also involves significant costs (Milligan, 2016). Therefore, in the absence of financial resources, the lack of stable housing and the transient nature of participants' lives, many viewed their homes more in an emotional or feeling sense as referring to the people who supported them rather than the physical space they occupied. One participant clearly articulated this sentiment that was captured in a field note:

> "Well, I don't really consider this my home to be honest with you. I eat and sleep here. I watch TV. I read a book. You know, I put a few things on my window ledge. But what makes this my home is what I try to surround myself with, you know? And the people that I choose to spend my time with. That's what makes it a home to me. Because I can be anywhere as long as I'm with people that care and love me, right?" (Mark)

Another participant, when asked to describe what home meant to them during an observation, pointed to their partner and said, "She is my home," highlighting the relational nature of home, particularly when traditional markers of home such as physical space, stability, and permanence may be absent or unpredictable. He later emphasized that the only thing he needed at the end of his life was to "have Maureen by my side." Similarly, during another observation, Ron emphasized that what mattered most was being around someone who understood them, identifying David as that source of support:

> "Well you gotta understand I just moved right, so home isn't really a word I would use…But if I had to answer, home means being able to talk to at least one person who understands you." When asked him who that was for him, he replied, "That would be David, sitting right here in this room."

The importance of community and social connection is further reflected in the story shared by a service provider, who recalled a resident's deep connection to her shelter. Despite the lack of traditional stability, this woman's long history with the place and the relationships she had cultivated there made it feel like home. When faced with eviction during a period of hospitalization, she asserted, "No, you can't do this. This is my home." And what she considered her home was the history. The fact that she has a history with the place, she's been there for a long time -- almost 10 years, people knew her. People, it's a place where she feels that she doesn't have to open up to all the stuff again."

Ultimately, this emerged as a prominent theme for participants. Regardless of the physical attributes of a space, being close to and surrounded by their community was of higher priority. Various other studies have also shown the importance of social and emotional support in relation to a person's sense of place within their communities and homes. This was also shown in this study, for some participants who articulated their preference to "be themselves." And to be accepted by other similar individuals. During an observation, one participant voiced that they felt accepted by their chosen family and friends because they were a lot like them and had similar histories and that was the truest form of care he had experienced, connecting to Tuan's (1997) framing of sense of place and belonging within a space.

Social Connection as Care

Building on the theme of home as a site for social connection, a closely related theme emerged: social connection as a form of care. Service providers deeply understood the significance of these connections and engaged in highly relational ways, at times prioritizing the relational aspect over the biomedical aspects of care. Service providers discussed the importance of "walking alongside" clients during this phase of life, learning about what mattered most to

them. Rather than assuming the role of experts, providers sought to understand people's circle of support and who they wished to have around them. An outreach worker shared their experience of connection being an undervalued element in their work:

> "And outreach work is quite invisible. Like that time that I spend sitting with someone, those conversations we have in the car, those trips to Tim Hortons and all of that stuff, that's not what someone's gonna look in someone's medical charts and read as the significant milestone in their care. But I think it cumulatively builds to, it's so impactful, it's so important. And again, it's that relationship building and care doesn't happen without that in my opinion."

A housing support worker expressed a similar sentiment, emphasizing the importance of emotional connection as a key component of care.

> "It's hard to say, we do provide care, but I feel that despite some of the examples I've mentioned in the last hour, I feel that the greatest care that we give is empathy, connection -- the sense that, you know, there's reason for hope."

Providers working with residents also recognized more unconventional ways to build connections and did their best to facilitate them.

> "And one of them I remember, is someone – I used to work overnight at the time, my first year and a half at [shelter] was overnight from 11:00 p.m. to 7:30 a.m., and that quiet time is when a lot of the night owls show up. And it's when a lot of the folks that don't feel well enough to connect with all the daytime hoopla would come out. And I would have a lot of time to chat with them and see if there's any way I could support them. And I remember one individual in particular who would come down, it started off as, you

know, “Can I just have a cigarette?” “Sure.” He was dying of cancer, but “Sure, you can have a cigarette.” And it ended up that it almost became a nightly routine where we'd go in the courtyard at [shelter], like 03:00 a.m. kind of thing, and he would open up a little bit more about the frustrations he was having and the difficulties he was experiencing knowing that the end was near.”

The importance of connection, regardless of whom it was with and when it happened was emphasized throughout most of the interviews with service providers. Another provider talked about the importance of residents maintaining existing connections in their community:

> “They’ll go out and it's usually to go and hang out with the folks they know. With the, I call it with the sidewalk. They go and connect with their folks. So, yeah, and it's not just drug-seeking behavior. It’s not just for the getting -- of something. Well, it is. It’s for the getting of feeling - connected to people. You know?”

Flexibility in these understandings and acknowledging that social connection is heavily connected to quality of life was also noted:

> “And I think that also in palliative care, we talk about quality of life, it's literally all about quality of life. It's like, how do we make the most out of the time you have left? So how does it not juxtapose that to move people into environments where like, they aren't… connection is everything…where people aren't able to have the connection that they want to have. For some people, that’s a lot of connection for some people, that’s none. And expect that they're going to have quality of life. And if that connection is limited, maybe they’re far away from their people, maybe they’re far away from…yeah, those spaces that make them feel like known and understood and seen.”

A service provider also highlighted that even though people didn't have robust social circles, they generally almost always have someone in their lives: "I notice with some folks I work with, their social network may not be massive, but there's like this one person, this one friend, who they're just constantly with. You know, this really, really, really, significant friend in their life." In the absence of familial connections, friends often take on this role and provide significant emotional and relational support.

Care Transitions and Place-Based Barriers to Social Connection

A key finding that emerged was the impact of transitions on participants. Four out of five adults were relocated at least once during the 12-month period in which the data were collected, underscoring the frequency of moves for people experiencing homelessness and the significant effects of these transitions on their mental and social well-being. The effects of these transitions varied and participants frequently had to sacrifice something in order to receive adequate care, whether it was the quality of physical care or the ability to remain with a chosen support.

A service provider shared a story about a participant who accessed the mobile care team and the effects of transferring adults to locations that may not be suitable:

> "Um, and then, and then (participant) moved into a, um, care setting, long-term care. Originally she was, she didn't have housing and she was accessing an emergency shelter on a night by night basis, just like a MAT program. Um, and she, um, at that time, then all of a sudden she's in this space, but she's an Indigenous woman in a long-term care facility that was run by the Salvation Army, which is a Christian organization. She's in her forties and she's surrounded by elderly people with dementia who are predominantly white and who are, you know, 40 years older than her. Um, and she was incredibly isolated."

Another case report developed from observational field notes and interviews illustrates the effect of transitions on participants' experiences of care.

Eric, a 70-year-old white man diagnosed with bladder cancer, was living in an inner-city shelter. Reserved and soft-spoken, he was often described as a "man of few words." A service provider who worked closely with him recalled their first encounter: "I was just starting the position, and he was one of the first people I met. He was living in an SRO, and he wanted to get out. He didn't have a private bathroom. It was just like, just a tiny room. It was dark. There was a lot of stairs, sometimes the elevator didn't work. So, I think it was more those kind of barriers that were particularly challenging. And at [new shelter] he had a private bathroom and a functioning elevator." These improvements were essential for Eric's health, as cancer treatment left him physically weak and further exacerbated his mobility challenges. Unlike many others in similar circumstances, Eric maintained some contact with his bio-legal family, primarily through phone calls. Though his family was largely uninvolved in his care, a service provider reflected on their bond: "They still loved each other. You know, that was pretty clear from both of them. And that was a family who still really cared." However, his daughter avoided visiting him at the shelter, expressing concerns about her safety in that environment. As Eric's illness progressed, he was transferred first to a long-term care facility and later to a hospital. This change provided him with greater access to his daughter, who began visiting regularly. A service provider observed: "His daughter started coming in quite frequently when he moved to the facility. She didn't feel safe visiting him at the other place – she never saw him, which was unfortunate. But she really came and was visiting him a lot in hospital too."

Eric's experience highlights the complex intersection of housing, health, and social connection. While improved living conditions supported his physical well-being, they did not always

facilitate meaningful relationships. In contrast, institutional care, often perceived as isolating, became the setting that finally allowed him greater opportunities to connect with his daughter.

Similar to Matthew and Brock, this setting facilitated social connection and ensured that support was present for Eric at the end of his life. However, this is not always the case. For many participants, being displaced and uprooted from their identified support systems caused significant distress and had profound impacts on their health. An outreach worker emphasized the broader challenges of these transitions and the critical importance of care continuity:

"And those moves can be super stressful for people that we work with, you're usually getting displaced out of community out of your those people that know you and [who] see you in this particular way, into this other environment where you're meeting all these new people, you're receiving care from strangers. And I think that there is, I haven't met anyone who moves into long term care who moves into hospital and says, "Okay, [mobile team] I don't need you anymore, like good riddance. It's been the opposite. It's definitely been people who, you know, want to maintain this connection [with the mobile team], people who asked me to be at their care planning meeting at that new facility with them. So, there's someone there that they know they're not just at a round table of eight people who are strangers talking to them about the care they're going to receive. And I think that is continuity of care. To me, it's obvious how that's important. It's like there's this trust built, there is this relationship built, those people kind of know you, you know them, you don't just parachute them into this foreign environment and then step back."

Although the hospital system was a positive experience for Matthew and Brock and for Eric, these places also often limited social connection for people, and in some instances, made people feel unsafe:

> “There’s so many barriers to the care that those people are able to provide because, say, for example, if someone’s in the hospital, those, that’s not always a safe place for those people to access. If someone needs to go and visit their friend on this floor of a shelter, there might be visitor restrictions.”
>
> “And, you know, if a client maybe ends up going into hospital or hospice, the somebodies will come and visit there, but it immediately becomes more difficult when it's no longer like, the familiar home setting, ‘we know what to do, we know how to get up there to see you.’ Suddenly, it's this very imposing hospital system.”
>
> “I can't remember what he said to me, but the impression that I left was like, he felt fearful in the hospital. And he felt like he was on a little island. Like it was, like this little island where everyone was surveilling him and everyone was watching him…he ended up dying in this environment where he felt incredibly unsafe. And yeah, sure, he was getting medical care, but he felt so unsafe. Yeah. And I just, and none of his friends, he had friends in community, and none of them were able to visit him because of the discrimination they experienced in that space. There was another guy who was in the hospital and his friends were getting profiled at the door and turned away like, because they just maybe looked like they were unhoused and all of those things.”

This was also the case in a long-term care facility where Todd was transferred. A nurse acknowledged people’s community support and the stigma that deterred people from visiting with their friends:

> “I had a new admission who lived downtown, and she brought over three friends. And just from knowing, just from back when working on Pandora, I know these three friends

> and I know their, like, their housing situation is similar and they were all in their room just talking, having a beer. And the staff were so uncomfortable ---- with that population coming in. And they really stuck to their visitation hours, and keeping the door open, which they didn't have to do because I think they were scared that they were all using in there, which they weren't. They were just casually - so, I think they like, they don't want to have friends over…"

Pathways Forward for Strengthening Social Connection

The interviews also highlighted practical solutions aimed at helping adults maintain their social connections when moved to more institutionalized settings. One participant suggested that providing more group activities could help bridge gaps in social engagement:

"They're very bored. So, I feel like those, but filling in the gap, I think, I don't know if, they could, if there were more activities that they could do as a group. So, or if there's places that they could go together as a group or a partner into the community, like, any sort of programming in the community, bringing programming in or having the actual resources to take people out as a group and do things together. But also, I really think that outreach piece too. Like, they do have, they do have a lot of close friends and family in the community. They just physically can't get to them."

Another participant emphasized the importance of outreach, suggesting the creation of outreach positions to facilitate transportation and social interaction:

> "I really think like, one of the most important things is if we had like, an outreach position or a couple of outreach positions where we could put people in, in their vehicles, like, if we had an outreach worker who drove them to their buddies downtown and picked them up and brought them back."

The availability of adequate spaces to host social interactions was also mentioned. A nurse suggested that creating a safe, designated area for substance use could promote more visits from family and friends. They also highlighted the rules around the patio that created more barriers for people to access.

"I think we need to provide them like an adequate space. That's, an adequate space. Like, we have two patios, the one patio is not being used. I feel like if we could use the second patio that friends and family like, knew that they could openly use substances out there. Like, they're, of course they're using substances on our smoking patio. But if you have like, ten people who live upstairs smoking out there and someone pulls out a pipe, they can feel like, ostracized and, or straight up told to put that shit away. And then they don't feel comfortable. So, if they had an actual safe space that they could use substances like, I feel like more family would come and feel open. And I, like, just like, the rules, I think around, like, visitation and the door being locked. And having to sign in and out, I don't know, it'd be nice to have like, an outdoor space that people could just, like, come and go, and pop by."

In most cases, people were transitioned due to escalating medical needs, which led to displacement from their social networks. Participants suggested that providing care in place could reduce these transitions, allowing adults to remain in familiar settings and surrounded by their support systems:

"We're strongly advocating right now -- Yeah. Not just for [housing facility], but – [service organization] generally, for the supportive, their supportive housing sites, to have a little private space where some medical tending can be done."

One participant expressed optimism about mobile outreach models, emphasizing their potential to enhance quality-of-life care beyond palliative needs:

> "I have high hopes for the [mobile] team. I mean, I have high hopes that this model will become -- a little bit more widespread. And not strictly for palliative outreach, but for quality-of-life outreach."

An outreach worker emphasized the need for more thoughtful and collaborative support during transitions, particularly when adults move into more institutionalized care facilities. They pointed out that, while these transitions may be necessary to meet changing health needs, they also raise important questions about how care is handed off and how relationships can be maintained. The outreach worker noted:

> "Because to be fair, sometimes they move into a care facility. And since their dimensions of health are met, they're much more healthy. They're maybe not as palliative anymore. But then it's like, what does that handoff look like in saying like, okay, you're at a place right now where like before our care was really, really needed. And now it's a little bit less needed. But we don't just want to abandon you. You know what I mean? Like, what does it look like to kind of connect you with like, what kind of support do you think you need now? Because what we were giving you before, maybe you don't need that anymore."

The outreach worker continued, highlighting the complexity of care transitions, emphasizing that they should not simply be seen as a procedural transfer from one team to another, but as a process that involves ensuring the person's ongoing needs are met and their relationships remain intact:

> “But there’s this element of like, again, it’s not just like, oh, we can transfer this person to another team. And it will be they’ll get the care they need, it’ll be just the same and all of this stuff because there isn’t those relationships yet. And all this stuff. I don’t think we should discontinue our care to someone that’s still alive. If we don’t know yet that all of those self-determined needs and wants that they have are being met by the new care team by that new care network that that environment that they’re in.”

They went on to stress the importance of ongoing communication and feedback directly from the person receiving care, rather than relying solely on reports from other healthcare professionals. This approach ensures that care remains aligned with the individual’s preferences, even as they transition between settings:

> “It shouldn’t happen until we know that. And that would be told to us by the person at the center of care. We can’t hear that from a nurse or a doctor that needs to come from like, hey, yeah, this new place is going really well. I’m not worried about this anymore, whatever.”

Chapter 4: Discussion and Conclusion

In this study, I explored how 'place' shaped experiences of care for precariously housed adults near end-of-life in Victoria, British Columbia. Collectively, the findings presented in this thesis demonstrate the various ways in which the concept of place can be understood to influence care at the end-of-life. Furthermore, they affirm that places do not possess a singular meaning or experience, rather, places are constructed in relation to lived experiences and influenced by power dynamics such as institutional policies, service provider views and relations among informal networks of care and clients (Hanrahan & Smith, 2020; Milligan, 2016). Participants' care experiences were shaped primarily by their access to social connections, which were often influenced by their living environment, demonstrating how power relations in various settings can shape social spaces such as the home, and consequently how place affects the relationships and social connections within these settings. The three related themes that emerged from this study were: (1) home as social connection with the related sub-theme of social connection as care, (2) care transitions and place-based barriers to social connection, and (3) pathways forward for strengthening social connection. The three case reports in chapter three illustrate how policies and stigma embedded in many of the settings in which people reside greatly limited participants' ability to engage with their social networks. However, in some instances, certain settings also offered opportunities for fostering social connection.

The first theme, home as social connection and the importance of social connection as care, highlights how participants' experiences of care were deeply tied to their ability to build and maintain relationships. For many, home was not simply a physical space but a site of connection, or disconnection, depending on their living circumstances. The presence or absence of supportive relationships within these spaces shaped their well-being, sense of belonging, and access to care. Participants who had stable environments with opportunities for social

engagement reported more positive care experiences, whereas those in restrictive or transient settings often faced isolation and limited access to support.

Frequent transitions and structural barriers further complicated participants' ability to maintain social connections and access care. Many participants experienced significant instability as they moved between shelters, hospitals, and other temporary living arrangements, disrupting relationships and limiting their ability to establish a sense of place. Institutional policies and stigma embedded within these settings often restricted opportunities for social interaction, reinforcing isolation. As a result, many participants faced significant challenges in accessing consistent emotional and social support, further shaping their end-of-life care experiences.

Despite these barriers, some participants and care providers identified ways to foster social connection, offering insights into potential pathways forward. Certain environments, such as hospices, provided opportunities for participants to maintain and build relationships and engage in community. Care approaches that prioritized relational connection helped mitigate some of the isolation participants faced. These findings highlight the importance of appreciating the social connections of adults so that they can be integrated into care models, particularly for those experiencing housing instability. For example, policies that prioritize stable, community-oriented housing and foster meaningful relationships can play a critical role in improving end-of-life care for precariously housed adults.

Although the biomedical aspect of healthcare should not be ignored, this study's findings suggest that emotional and social needs are frequently neglected or undervalued. While both physical and emotional needs hold equal significance, societal values influence their prioritization process (Wiles, 2024), often marginalizing social connections and emotional

support, which have been demonstrated to be crucial in end-of-life care experiences. Investigating what home meant for participants shed light on the importance of the people around them particularly when their housing was unstable. This study reveals a critical gap in the healthcare system's understanding of the importance of social networks for people experiencing housing insecurity. Despite assumptions that precariously housed populations lack reliable or positive social connections, the findings suggest that many adults have strong connections, both bio-legal families, but more often not that they rely on for support. This result resonates with research by Bryant (2016), who similarly argues that the healthcare system's failure to recognize these social networks as legitimate sources of support contributes to the marginalization of precariously housed adults in end-of-life care. Moving away from the traditional view of the nuclear family as the default caregiver model, and instead valuing diverse forms of social support, would contribute to more equitable care practices (Vásquez-Vera et al., 2017). Acknowledging and supporting these social connections, particularly in precarious housing contexts, is essential to improving care for marginalized groups (Bryant, 2016; Chan et al., 2024)

The importance of "walking alongside" clients, as described by service providers, reflects a shift towards a relational model of care that prioritizes understanding adults' needs, preferences, and social networks. This approach echoes the work of McGrath (2020), who advocates for the incorporation of relational care models in palliative settings to enhance the dignity and quality of life of those nearing the end-of-life. By engaging with clients' social supports and respecting their relational networks, service providers challenge the traditional view of care as solely a medical or familial responsibility. This shift is particularly crucial for marginalized populations, whose social networks may differ and whose end-of-life care needs may not align with mainstream palliative care paradigms (Stajduhar et al., 2019).

A contribution of this research is to weave together geographic and health equity perspectives, to illustrate how 'place,' encompassing physical location, sense of place and the broader socio-political environment, shapes access to palliative care. The concept of "care landscapes," as discussed by Wiles (2024), is central to understanding how resources, policies, and social structures interact to influence where and how care is delivered. My findings reveal that precariously housed adults are often excluded from mainstream palliative care options due to a combination of geographic, structural, and policy-based barriers. The prioritization of stable housing as a precondition for receiving quality end-of-care reflects broader systemic inequalities in healthcare, where the needs of marginalized populations are deprioritized based on their housing status (Chan et al., 2024; Bryant, 2016). This disparity in access to care is particularly concerning given the increasing body of literature that links social support and quality of life with improved health outcomes at the end-of-life (Gomes et al., 2013; Hudson et al., 2017). It is evident that housing serves as a crucial social determinant of health, intricately linking social connections to housing environments. Thus, we need to pay greater attention to the impact of transitions, uprootings and relocations on social connections, examining modifications to current housing policies in order to foster social connections for adults approaching the end-of-life.

Conclusion

Canadian policy debates are increasingly focused on the challenges presented by an aging population and the anticipated demand for palliative care. However, it is crucial to understand that adults requiring palliative care are not merely a homogeneous group of older Canadians. Rather, they represent a varied demographic influenced by a complex interplay of social, economic, cultural, political, historical, geographical, and physical factors. These intersecting

influences significantly affect their palliative care needs, their social connectivity, and ultimately, their access to these resources.

Housing greatly affects adults' access to care, and is significantly influenced by regional differences in geography, economy, demographics, and cultural standards. Moreover, access is closely linked to one's social position and the associated advantages or disadvantages within larger power structures as these systemic factors shape opportunities, choices, perceptions, and the ability to obtain necessary services. When policies overlook these realities, especially regarding those who need particular and specialized types of support, they risk exacerbating existing disparities in care access. Given the complex nature of individual experiences and the impact of power dynamics on service availability, it is crucial to apply both geographic and health equity perspectives to better illuminate the health disparities precariously housed adults face. Combining these perspectives is valuable to the field of palliative care as it highlights the importance of place in care provision, an aspect that has been largely overlooked when considering those who live with housing insecurity and precarity. In conclusion, this thesis critically examined the social dimensions of health and their relation to end-of-life care, with a specific focus on housing and social connection. The findings ultimately demonstrate how 'place' influenced adults' end-of-life care experiences by mediating their ability to engage with their social supports and communities. This suggests that integrating practices that value connection can strengthen the person-centred, holistic, and social aspects of palliative care that are foundational to equitable end-of-life care experiences.

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Appendix A – Certificate of Ethics Approval

University of Victoria

Certificate of Ethical Approval: Renewal for Harmonized Minimal Risk Behavioural Study

University of Victoria
Human Research Ethics Board
Michael Williams Building, R. B202 PO Box 1700
STN CSC
Victoria, BC V8W 2Y2
Tel: 250-472-4545

Also reviewed and approved by:

- **UBC Behavioural Research Ethics Board**
- **Island Health**

Principal Investigator:	**Primary Appointment:**	**Board of Record REB Number:**	**REB Number: H22-00313**
Kelli I. Stajduhar	University of Victoria	BC22-0118	PAA #: H22-00313-A004

Study Title:
Caregiving for Vulnerable and Marginalized Older Adults at the End of Life

Approval Date: January 11, 2024 **Expiry Date: January 11, 2025**

Research Team Members:	Sally E. Thorne, UBC faculty Marilou Gagnon, UVic faculty Fred Chou, UVic faculty Kara Whitlock, UVic Project Coordinator Ashely Molinson, UVic Research Manager and UVic PhD student Amber Bourgeois, UVic PhD student Fraser Black, Island Health Jill Gerke, Island Health Damien Contandriopoulos, UVic faculty Alexandra Stewart, UVic Research Assistant Carren Dujela, UVic Research coordinator
Sponsoring Agencies:	- Canadian Institutes of Health Research (CIHR)
Documents included in this approval:	N/A
Document(s) acknowledged with this submission:	**Summary Report(s)** There are no items to display

This ethics approval applies to research ethics issues only and does not include provision for any administrative approvals required from individual institutions before research activities can commence.

The Board of Record (as noted above) has reviewed and approved this study in accordance with the most recent requirements of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2).

The "Board of Record" is the Research Ethics Board delegated by the participating REBs involved in a harmonized study to facilitate the ethics review and approval process.

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Appendix B – Mobile Team Consent Form

Caregiving for Vulnerable and Marginalized Older Adults at the End of Life

About the study:

Thank you for accepting our invitation to be part of the "*Caregiving for Vulnerable and Marginalized Older Adults at the End of Life*" research project with Dr. Kelli Stajduhar, from the University of Victoria. This research project, funded by the Canadian Institutes for Health Research builds on our previous work focused on improving access to and quality of palliative and end-of-life care for people who are homeless and vulnerably housed. That work has highlighted the great variability in how 'family' and 'caregiving' are conceived and enacted.

Purpose and objectives:

Specifically, our objectives are to:

(1) Understand and describe how caregiving and caregivers are constructed among structurally vulnerable people, characterizing who these caregivers are and the support they provide.
(2) Describe what caregivers do in relation to the palliative caregiving role and the perceived impact on them.
(3) Characterize the physical spaces (e.g., on the street, shelters, transitional housing) in which caregiving occurs in the context of structural vulnerability and their role in shaping caregiving relationships and support.
(4) Elucidate the social-structural and wider organizational and socio-political contexts that shape caregivers' everyday experiences of caring for structurally vulnerable people at EOL.

Your participation must be free and voluntary. You can withdraw at any time. The purpose of observation is to gain a better understanding and insight into the family caregiving role. This includes who provides support, what that support looks like, and the interplay between the healthcare system and informal caregivers.

Importance of this research

From this research we anticipate making actionable recommendations that will allow us to work toward the development of policies, programs and services that will promote equitable, consistent, and sustainable services to meet the needs of caregivers of structurally vulnerable older adults at the EOL in Canada.

Participants selection

The current project will focus on forming an in-depth understanding of family caregiving in the context of end-of-life (EOL) care for older adults experiencing structural vulnerability. You have been invited to participate in this study because you work on a mobile, inner city palliative care team supporting structurally vulnerable adults with life limiting chronic health issues.

What is involved?

With your consent, we would like to join and take notes on the visits (approx. 2-4 hours each) with you and your clients. Before each visit, the researcher will seek consent to attend and will only observe when both you and the client consent.

The research assistant will take note of how care and support provided by others is discussed, described, and observed in relation to your clients. They may also ask you or the client a few questions to clear up anything that they do not understand. The researcher will not be checking or judging your work, observations will not be shared with the service agency or the client.

Risks and Benefits:

Some people feel embarrassed, uncomfortable, anxious, or get upset when they share their experiences. However, people who have participated in our research have often found it helpful to talk with someone about their experiences. Some say it is the first time that they have been able to tell their story. You do not have to answer any question you do not wish to answer. There are no right or wrong answers; we are seeking your opinion and insights. If at any time you find the observation intrusive, upsetting, or interfering with care, you can request we leave temporarily or withdraw from it all together without consequence. If you identify gaps in care or knowledge, we invite you share this with us as we may have resources available to assist in your practice.

There may or may not be direct benefits to you from taking part in the study. We expect findings will improve services and supports for the caregivers of structurally vulnerable older adults at the EOL in Canada.

Participants will be advised if they have or may have come into contact with an individual who has tested positive for COVID-19. Contact information for participants will be stored in a separate file from research data in the event that follow up is needed.

Do I have to take part?

You are free to participate or not. There are no consequences to not participating. Joining this study does not waive any of your legal rights to research-related harm. If you decide to participate and then change your mind later, you can withdraw without any consequences or explanation. If you leave the study before it ends, we will ask for your consent to use your interview as part of the research.

Will I receive payment for taking part?

You will not receive any monetary benefits from participating in this interview.

Confidentiality & how my personal information will be used

What you share with us is confidential and private. No service providers or users will see your interview. Involvement in the study will not impact your employment and your interview

recording including the transcript will not be shared with your employer. No one other than the University of Victoria staff will have access to your audio recording. Your name will be replaced with a unique identifier.

In the event names of clients or colleagues are provided when discussing examples, the research staff will replace this information with pseudonyms.

You are consenting to the use of Zoom for the interviews (a videoconferencing program that is free for participants). The Zoom link will be password protected, meaning only persons with the password will be able to enter the meeting room. You will be provided with the password prior to the meetings starting. You are welcome to mute your camera and/or microphone during the course of our meeting when they aren't needed. Zoom servers are located outside Canada and Zoom stores users' names and usage information outside of Canada. Any study related videos sent outside of Canadian borders may increase the risk of disclosure of information because of the laws in those countries. The interview video will likely go through servers outside of Canada and thus may increase the risk of disclosure. Please note that we will not store any meeting video or audio recordings in the Zoom server. All meeting recordings will be stored directly on to the University of Victoria's secure servers.

All our files are stored in a locked office and on encrypted computers at the University of Victoria and only a few people on the research team have access. Any reports or presentations made from the findings of this study will not use your name or other details that could reveal your identity.

Future Use of Data

Researchers will retain digital de-identified data sets indefinitely. Electronic data from this study will be retained for future graduate students and further secondary analysis by Dr. Stajduhar, research ethics approval will be sought before any secondary analysis is done with this data. Data will be stored securely at the University of Victoria and in compliance with the highest standard of data management practices.

Disposal of Study documents and recordings

We will scan all paper copies and save them electronically. We will shred all paper copies 5 years after the completion of this research study.

Sharing the findings

We plan to share what we have learned from our study in many ways. We will write a final report that will be shared with you if you like. We will do presentations and workshops in the community, with government, and service providers to share what we have learned with community members. We will also make presentations at meetings in Canada and maybe other

parts of the world to share our results and publish articles in academic magazines and journals which may be available on the internet.

Who should I contact if I need more information or help?

For more information about the research, please contact Kara Whitlock, project coordinator at (250) 472-4465 or kdwhitlo@uvic.ca. You are also welcome to contact the principal investigator directly – Kelli Stajduhar, University of Victoria, (250) 721-7487 or kis@uvic.ca.

For questions or concerns about your rights as a research participant, please contact the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca.

CONSENT

Your signature below indicates that:

1. All sections of this Consent form have been explained to your satisfaction,
2. You understand the requirements, risks, potential and responsibilities of participating in the research project,
3. You understand that your interview will be video recorded,
4. You understand how your information will be accessed, collected and used, and
5. Your questions have been answered by the researchers.

Name of Participant (print)	Signature	Date

Name of Person Administering Informed Consent	Signature	Date

Role of Person Administering Informed Consent

A copy of this consent will be provided to you, and the researcher will take a copy.

Appendix C – Info Sheet and Consent to Contact

Research Project: *Caregiving for Vulnerable and Marginalized Older Adults at the End of Life*

Background: The University of Victoria is working on research with inner city palliative care services across Canada. Studies on family caregiving for people who are dying often assume that family members are all the same. They are usually housed and financially stable with family and friends who can help them. But not all families are like this, and not all seriously ill people have a safe and secure home or family members to rely on. The Canadian Institutes for Health Research has awarded us funding to meet with people in Victoria, Calgary and Toronto to better understand these networks of care and support.

Recruitment Script:

My name is _____ and I am involved in research at the University of Victoria, and they want to talk with people who have experiences of supporting someone in poor health. I believe they would really benefit from talking with you about your experience. Is this something you might be interested in learning more about? □ YES □ NO

(if yes) If you are interested in chatting with [research staff name], I can give you [staff] phone number or I can let [staff] know to get in touch with you. What would you prefer?

□ YES they will contact □ YES staff contacts them □ Other _____

[If staff contacts them] Are you okay with me telling [staff] how to reach you?

□ YES □ NO What is the best way for [staff] to get in touch with you?

Note phone number or email and any other details: _____
_____
_____
_____

Date: _____

Throughout the interaction, please be sensitive to your potential power-over position as discussed in the Oath of Confidentiality.

Expiration Date: 24 months after the date signed.

Appendix D – Observational Consent Form

Research Project: *Caregiving for Vulnerable and Marginalized Older Adults at the End of Life*

Background and Purpose of the Study

Thank you for accepting our invitation to be part of the "*Caregiving for Vulnerable and Marginalized Older Adults at the End of Life*" research project with Dr. Kelli Stajduhar, from the University of Victoria. This research project, funded by the Canadian Institutes for Health Research builds on our previous work focused on improving access to and quality of palliative and end-of-life care for people who are homeless and vulnerably housed. One thing we learned from this work is that we don't know how 'family' and 'caregiving' are provided or understood when it comes to structurally vulnerable people.

You have been invited to participate in this study because you have a connection with the Palliative Outreach Resource Team (PORT) team. Either as someone who is structurally vulnerable, unhoused or precariously housed, and has a life limiting chronic health issue or as someone who supports a person who is connected with the PORT team.

This project focuses on forming an in-depth understanding of family caregiving in the context of end-of-life (EOL) care for older adults experiencing structural vulnerability. The purpose of this interview is to talk with you about either receiving or giving care in the inner-city community.

Specifically, our goals are to: (1) Understand and explain how caregiving and caregivers are seen among structurally vulnerable people, describing who these caregivers are and the support they provide; (2) Explain what caregivers do when they take on the role of palliative caregiving and how it affects them; (3) Describe the places (e.g., on the street, shelters, transitional housing) where caregiving happens in the context of structural vulnerability and how these places affect caregiving relationships and support; and (4) Explore the social-structural and wider organizational and socio-political factors that affect caregivers' everyday experiences when caring for structurally vulnerable people towards the end of life.

Through this research, we expect to offer practical suggestions that can help us create policies, programs, and services. These recommendations aim to ensure fair, reliable, and lasting support for caregivers of structurally vulnerable older adults in Canada.

Your participation must be free and voluntary. You can withdraw at any time. You have been invited because we know that family has an important role when someone is living with serious advanced illness at home. We would like to know more about your experience.

What is involved?

With your consent, we would like to join and take notes on the visits (approx. 2-4 hours each) with you and your clients. Before each visit, the researcher will seek consent to attend and will only observe when both you and the client consent.

The research assistant will take note of how care and support provided by others is discussed, described, and observed in relation to your clients. They may also ask you or the client a few

questions to clear up anything that they do not understand. The researcher will not be checking or judging your work, observations will not be shared with the service agency or the client.

Risks and Benefits:

Some people feel embarrassed, uncomfortable, anxious, or get upset when they share their experiences. However, we are not there to judge you and there are no right or wrong answers. If at any time you find talking with us upsetting, you can take a break or leave it altogether without consequence. We cannot promise the study will help you directly, but some people find it helpful to talk to someone about their experiences. The research will give you the opportunity to share through your own words and experiences of how care is given and received. This will help others (service providers and decisions makers) better understand the unique challenges and strengths that can be overlooked. We believe the experiences you share with us will help to improve services for people in the future.

There may or may not be direct benefits to you from taking part in the study. We expect findings will improve services and supports for the caregivers of structurally vulnerable older adults at the end of life in Canada.

Participants will be advised if they have or may have come into contact with an individual who has tested positive for COVID-19. Contact information for participants will be stored in a separate file from research data in the event that follow up is needed.

Do I have to take part?

You are free to participate or not. There are no consequences to not participating. Joining this study does not waive any of your legal rights to research-related harm. If you decide to participate and then change your mind later, you can withdraw without any consequences or explanation. If you leave the study before it ends, we will ask for your consent to use your interview as part of the research.

Will I receive payment for taking part?

You will receive $50 for each observation.

Confidentiality & how my personal information will be used.

Your full name and contact details will be known ONLY to the research team. So that you cannot be identified, your name will be replaced with a unique study number. Only this number is used on any research-related information collected about you during this study, so that your identity [your name or any other information that could identify you] will be kept confidential.

What you say and do during the observation is kept confidential. The research may witness something that they think should be shared with another professional or service or that the researcher believes they have a legal obligation to report. If something like this happens, then after the observation the researcher may talk to you about the benefits of sharing this

information. The researcher may also ask for advice from other people in the research team but will maintain your privacy as far as possible.

All notes are stored on a computer at the University of Victoria. Only a few people on the research team have access to the encrypted computer. Any reports or presentations made from the findings of this study will not use your name or other details that could reveal your identity.

You will not be identified by name in any published results.

All our files are stored in a locked office and on encrypted computers at the University of Victoria and only a few people on the research team have access. Any reports or presentations made from the findings of this study will not use your name or other details that could reveal your identity.

Future Use of Data

Following CIHR-funding guidelines, researchers will retain digital de-identified data sets indefinitely. Electronic data from this study will be retained for future graduate students and further secondary analysis by Dr. Stajduhar, research ethics approval will be sought before any secondary analysis is done with this data. Data will be stored securely at the University of Victoria and in compliance with the highest standard of data management practices.

Disposal of Study documents and recordings

We will scan all paper copies and save them electronically. We will shred all paper copies 5 years after the completion of this research study.

Sharing the findings

We plan to share what we have learned from our study in many ways. We will write a final report that will be shared with you if you like. We will do presentations and workshops in the community, with government, and service providers to share what we have learned with community members. We will also make presentations at meetings in Canada and maybe other parts of the world to share our results and publish articles in academic magazines and journals which may be available on the internet.

Who should I contact if I need more information or help?

For more information about the research, please contact Ashley Mollison, project manager at (250) 472-5501 or mollison@uvic.ca. If you have been diagnosed with cancer, then you may be meeting with Amber Bourgeois, you can reach her amberbou@uvic.ca or (250) 472-5501. You are also welcome to contact the principal investigator directly – Kelli Stajduhar, University of Victoria, (250) 721-7487 or kis@uvic.ca.

For questions or concerns about your rights as a research participant, please contact the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca.

CONSENT

Your signature below indicates that:

6. All sections of this Consent form have been explained to your satisfaction,
7. You understand the requirements, risks, potential and responsibilities of participating in the research project,
8. You understand that your interview will be video recorded,
9. You understand how your information will be accessed, collected and used, and
10. Your questions have been answered by the researchers.

Name of Participant (print)	Signature	Date

Name of Person Administering Informed Consent	Signature	Date

Role of Person Administering Informed Consent

A copy of this consent will be provided to you, and the researcher will take a copy.

Appendix E – Adult Interview Consent Form

Research Project: *Caregiving for Vulnerable and Marginalized Older Adults at the End of Life*
Background and Purpose of the Study

Thank you for accepting our invitation to be part of the "*Caregiving for Vulnerable and Marginalized Older Adults at the End of Life*" research project with Dr. Kelli Stajduhar, from the University of Victoria. This research project, funded by the Canadian Institutes for Health Research builds on our previous work focused on improving access to and quality of palliative and end-of-life care for people who are homeless and vulnerably housed. One thing we learned from this work is that we don't know how 'family' and 'caregiving' are provided or understood when it comes to structurally vulnerable people.

You have been invited to participate in this study because you have a connection with the Palliative Outreach Resource Team (PORT) team. Either as someone who is structurally vulnerable, unhoused or precariously housed, and has a life limiting chronic health issue or as someone who supports a person who is connected with the PORT team.

This project focuses on forming an in-depth understanding of family caregiving in the context of end-of-life (EOL) care for older adults experiencing structural vulnerability. The purpose of this interview is to talk with you about either receiving or giving care in the inner-city community.

Specifically, our goals are to: (1) Understand and explain how caregiving and caregivers are seen among structurally vulnerable people, describing who these caregivers are and the support they provide; (2) Explain what caregivers do when they take on the role of palliative caregiving and how it affects them; (3) Describe the places (e.g., on the street, shelters, transitional housing) where caregiving happens in the context of structural vulnerability and how these places affect caregiving relationships and support; and (4) Explore the social-structural and wider organizational and socio-political factors that affect caregivers' everyday experiences when caring for structurally vulnerable people towards the end of life.

Through this research, we expect to offer practical suggestions that can help us create policies, programs, and services. These recommendations aim to ensure fair, reliable, and lasting support for caregivers of structurally vulnerable older adults in Canada.

Your participation must be free and voluntary. You can withdraw at any time. You have been invited because we know that family has an important role when someone is living with serious advanced illness at home. We would like to know more about your experience.

What is involved?

We would like to meet with you either in person or virtually, for about an hour. Interviews will be scheduled at your convenience.

Risks and Benefits:

Some people feel embarrassed, uncomfortable, anxious, or get upset when they share their experiences. However, we are not there to judge you and there are no right or wrong answers. If

at any time you find talking with us upsetting, you can take a break or leave it altogether without consequence. We cannot promise the study will help you directly, but some people find it helpful to talk to someone about their experiences. The research will give you the opportunity to share through your own words and experiences of how care is given and received. This will help others (service providers and decisions makers) better understand the unique challenges and strengths that can be overlooked. We believe the experiences you share with us will help to improve services for people in the future.

There may or may not be direct benefits to you from taking part in the study. We expect findings will improve services and supports for the caregivers of structurally vulnerable older adults at the end of life in Canada.

Participants will be advised if they have or may have come into contact with an individual who has tested positive for COVID-19. Contact information for participants will be stored in a separate file from research data in the event that follow up is needed.

Do I have to take part?

You are free to participate or not. There are no consequences to not participating. Joining this study does not waive any of your legal rights to research-related harm. If you decide to participate and then change your mind later, you can withdraw without any consequences or explanation. If you leave the study before it ends, we will ask for your consent to use your interview as part of the research.

Will I receive payment for taking part?

You will receive $50 for each interview.

Confidentiality & how my personal information will be used.

Your full name and contact details will be known ONLY to the research team. So that you cannot be identified, your name will be replaced with a unique study number. Only this number is used on any research-related information collected about you during this study, so that your identity [your name or any other information that could identify you] will be kept confidential.

What you say in the interviews is kept confidential. You may say something that the researcher thinks should be shared with another professional or service or that the researcher believes they have a legal obligation to report. If you do say something like this, then after the session the researcher may talk to you about the benefits of sharing this information. The researcher may also ask for advice from other people in the research team but will maintain your privacy as far as possible. All notes are stored on a computer at the University of Victoria. Only a few people on the research team have access to the encrypted computer. Any reports or presentations made from the findings of this study will not use your name or other details that could reveal your identity. You will not be identified by name in any published results.

All our files are stored in a locked office and on encrypted computers at the University of Victoria and only a few people on the research team have access. Any reports or presentations

made from the findings of this study will not use your name or other details that could reveal your identity.

Future use of data

Following CIHR-funding guidelines, researchers will retain digital de-identified data sets indefinitely. Electronic data from this study will be retained for future graduate students and further secondary analysis by Dr. Stajduhar, research ethics approval will be sought before any secondary analysis is done with this data. Research ethics approval will be sought before any secondary analysis is done with this data. Data will be stored securely at the University of Victoria and in compliance with the highest standard of data management practices.

Disposal of study documents and recordings

We will scan all paper copies and save them electronically. We will shred all paper copies 5 years after the completion of this research study.

Sharing the Findings:

We plan to share what we have learned from our study in many ways. We will write a final report that will be shared with you, if you like, and we will do presentations and workshops in the community, with government, and service providers to share what we have learned with community members. We will also make presentations at meetings in Canada and maybe other parts of the world to share our results and publish articles in academic magazines and journals which may be available on the internet.

Who should I contact if I need more information or help?

For more information about the research, please contact Ashley Mollison, project manager at (250) 472-5501 or mollison@uvic.ca. If you have been diagnosed with cancer, then you may be meeting with Amber Bourgeois, you can reach her amberbou@uvic.ca or (250) 472-5501. You are also welcome to contact the principal investigator directly – Kelli Stajduhar, University of Victoria, (250) 721-7487 or kis@uvic.ca.

For questions or concerns about your rights as a research participant, please contact the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca.

CONSENT

Your signature below indicates that:

1. All sections of this Consent form have been explained to your satisfaction,
2. You understand the requirements, risks, potential and responsibilities of participating in the research project,
3. You understand how your information will be accessed, collected and used, and
4. Your questions have been answered by the researchers.

Name of Participant (print)	Signature	Date

Name of Person Administering Informed Consent	Signature	Date

_____

Role of Person Administering Informed Consent

Appendix F – Observational Field Note Template

Date:

Location:

Time:

Participant codes:

Researcher:

Situating self: Take a few minutes to describe where you are at today

Section 1: Observational Notes

These notes are descriptive accounts of your observations as a third-party observer. In this section you will describe the type of things detailed in the observation guide. One way to think of these fieldnotes is as a descriptive story. Make your fieldnotes as descriptive and detailed as you can. The more colorful and clear they are the more the rest of the research team will be able to visualize what you're describing (include your sense perception like sounds, smells, temperature).

Section 2: Reflexive Notes

These are your own reflections on the observation. Be sensitive to your own bias and avoid making generalizations and judgements. Also reflect on your own professional and social positioning that may have influenced the research process, participants' reactions to you as an observer, and the dynamics of your relationship with participants. Describe any personal feelings/interpretations that you may have based on the observation, relating it to other observations if applicable. Also make note here of questions that should be asked in interviews and any themes that you're seeing.

Appendix G – Service Provider Interview Consent Form

Research Project: *Caregiving for Vulnerable and Marginalized Older Adults at the End of Life*

About the Study:

Thank you for accepting our invitation to be part of the "*Caregiving for Vulnerable and Marginalized Older Adults at the End of Life*" research project with Dr. Kelli Stajduhar, from the University of Victoria. This research project, funded by the Canadian Institutes for Health Research builds on our previous work focused on improving access to and quality of palliative and end-of-life care for people who are homeless and vulnerably housed. That work has highlighted the great variability in how 'family' and 'caregiving' are conceived and enacted.

The current project will focus on forming an in-depth understanding of family caregiving in the context of end-of-life (EOL) care for older adults experiencing structural vulnerability. You have been invited to participate in this study because of your professional involvement in supporting structurally vulnerable adults living in inner city settings with life limiting chronic health issues.

Specifically, our objectives are to: (1) Understand and describe how caregiving and caregivers are constructed among structurally vulnerable people, characterizing who these caregivers are and the support they provide; (2) Describe what caregivers do in relation to the palliative caregiving role and the perceived impact on them; (3) Characterize the physical spaces (e.g., on the street, shelters, transitional housing) in which caregiving occurs in the context of structural vulnerability and their role in shaping caregiving relationships and support; and (4) Elucidate the social-structural and wider organizational and socio-political contexts that shape caregivers' everyday experiences of caring for structurally vulnerable people at EOL.

From this research we anticipate making actionable recommendations that will allow us to work toward the development of policies, programs and services that will promote equitable, consistent and sustainable services to meet the needs of caregivers of structurally vulnerable older adults at the EOL in Canada.

Your participation must be free and voluntary. You can withdraw at any time. The purpose of the one-on-one interviews is to solicit information and insights into the role of family caregivers, who provides support, what support looks like, and the interplay between the health care system and informal caregivers.

What is required for me to participate?

We would like to meet with you virtually, for about an hour. Interviews will be scheduled at your convenience, including during work hours.

Risks and Benefits:

Some people feel embarrassed, uncomfortable, anxious, or get upset when they share their experiences. However, people who have participated in our research have often found it helpful to talk with someone about their experiences. Some say it is the first time that they have been able to tell their story. You do not have to answer any question you do not wish to answer. There

are no right or wrong answers; we are seeking your opinion and insights. If at any time you find the discussion or telling of your experiences upsetting, you are welcome to leave the interview temporarily to compose yourself or withdraw from it all together without consequence. We can also offer you further support through a list of available resources.

There may or may not be direct benefits to you from taking part in the study. We expect findings will to improve services and supports in the inner-city community.

Participants will be advised if they have or may have come into contact with an individual who has tested positive for COVID-19. Contact information for participants will be stored in a separate file from research data in the event that follow up is needed.

Do I have to take part?

You are free to participate or not. There are no consequences to not participating. Joining this study does not waive any of your legal rights to research-related harm. If you decide to participate and then change your mind later, you can withdraw without any consequences or explanation. If you leave the study before it ends, we will ask for your consent to use your interview as part of the research.

Will I receive payment for taking part?

You will not receive any monetary benefits from participating in this interview.

Confidentiality & How my personal information will be used

What you share with us is confidential and private. No service providers or users will see your interview. Involvement in the study will not impact your employment and your interview recording including the transcript will not be shared with your employer. No one other than the University of Victoria staff will have access to your audio recording. Your name will be replaced with a unique identifier.

In the event names of clients or colleagues are provided when discussing examples, the research staff will replace this information with pseudonyms.

You are consenting to the use of Zoom for the interviews (a videoconferencing program that is free for participants). The Zoom link will be password protected, meaning only persons with the password will be able to enter the meeting room. You will be provided with the password prior to the meetings starting. You are welcome to mute your camera and/or microphone during the course of our meeting when they aren't needed. Zoom servers are located outside Canada and Zoom stores users' names and usage information outside of Canada. Any study related videos sent outside of Canadian borders may increase the risk of disclosure of information because of the laws in those countries. The interview video will likely go through servers outside of Canada and thus may increase the risk of disclosure. Please note that we will not store any meeting video or audio recordings in the Zoom server. All meeting recordings will be stored directly on to the University of Victoria's secure servers.

All our files are stored in a locked office and on encrypted computers at the University of Victoria and only a few people on the research team have access. Any reports or presentations made from the findings of this study will not use your name or other details that could reveal your identity.

Future Use of Data

Researchers will retain digital de-identified data sets indefinitely. Electronic data from this study will be retained for future graduate students and further secondary analysis by Dr. Stajduhar, research ethics approval will be sought before any secondary analysis is done with this data. Data will be stored securely at the University of Victoria and in compliance with the highest standard of data management practices.

Disposal of Study documents and recordings

We will scan all paper copies and save them electronically. We will shred all paper copies 5 years after the completion of this research study.

Sharing the findings

We plan to share what we have learned from our study in many ways. We will write a final report that will be shared with you if you like. We will do presentations and workshops in the community, with government, and service providers to share what we have learned with community members. We will also make presentations at meetings in Canada and maybe other parts of the world to share our results and publish articles in academic magazines and journals which may be available on the internet.

Who should I contact if I need more information or help?

For more information about the research, please contact Amber Bourgeois, PhD candidate at amberbou@uvic.ca. You are also welcome to contact the principal investigator directly – Kelli Stajduhar, University of Victoria, (250) 721-7487 or kis@uvic.ca.

For questions or concerns about your rights as a research participant, please contact the Human Research Ethics Office at the University of Victoria at 250-472-4545 or ethics@uvic.ca.

CONSENT

Your signature below indicates that:

1. All sections of this Consent form have been explained to your satisfaction,
2. You understand the requirements, risks, potential and responsibilities of participating in the research project,
3. You understand that the interview will be video recorded,
4. You understand how your information will be accessed, collected and used, and
5. Your questions have been answered by the researchers.

Name of Participant (print)	Signature	Date

Name of Person Administering Informed Consent	Signature	Date

Role of Person Administering Informed Consent

A copy of this consent will be provided to you, and the researcher will take a copy.

Appendix H – Service Provider Interview Guide

Date and time:

Location:

Participant code:

Preamble:

One of the things that we see in palliative care is the important role that family members play in supporting people who have a life-limiting illness. We also know that in our work with people who are living in contexts of inequity like homelessness and poverty that there are not always family members in the tradition sense available for care. Our project is focusing on how people who are marginalized and vulnerable get support and care when they are dying and from whom. In other words we are interested in questions like:

- Who provides care and support?,
- What do these people do?
- Where does caregiving take place?
- What kinds of things influence how people get care?

Go through the consent form, ask them to sign, and turn on your recorder

While we are chatting please think about the people you interact with and their networks as we go through the questions. As part of this project, we have been observing and talking to people who are living with serious illness and the folks in their lives. We'd like to talk with you because we've heard about/seen your work in this area and we'd like to talk to you more about this.

Potential questions:

- Can you tell me a little bit about your work? What do you do? What is your role?
    - I'm wondering if you can talk about [support for specific person] or a time that you were involved in supporting someone with a life-limiting illness?
    - How do you know [person]? How did you come to support them? (prompts: what was happening at that time? When did you meet them?)
    - Can you tell me a bit about [person's] situation (housing, family support, what services they are accessing, etc.)?
    - What is your role? What are the tasks/activities that you do? (prompts: transportation, coordinating appointments/treatment, food, housing, prescriptions/medications, emotional support, check ins, spiritual care) How often are you seeing them?
    - Who else is involved in the care? (Prompt: a neighbor, a bio family member, shelter workers, etc.)
    - If there are other people involved in supporting the client, what is their role in support and care? What do they do? (prompts: transportation, coordinating appointments/treatment, food, housing, prescriptions/medications, emotional support, check ins, spiritual care)

I'd like to turn our attention now to better understanding the relationship between the client and the various "caregivers" they may come in contact with. We've learned in our previous research that sometimes these "caregiving" relationships are sometimes complex when working with folks who are experiencing inequities and support comes in various ways and forms. Sometimes clients do have connection with their blood or legal family members who provide care and support and sometimes they don't. Can you talk a little bit about that and what your experience has been?

- [Referring to the person's support network] How do relationships between supporters work (e.g., between family and services, etc.). Can you give a couple of examples that stand out for you? What went well in this instance? What didn't go as well as you might have hoped?
- If we think about a persons' caregivers or others in their life, what tensions or challenges have arisen? Can you give an example?
- Have you worked with people who have had very little support? What happens for clients when there is no "caregiver"? Who provides care and support in these instances? How do those gaps get filled? Who fills the gaps?
- Who do you think should be there to fill gaps, but isn't? Why? What should they be doing?

I'd now like to ask a few questions about what we might do to better support these various kinds of "caregivers"

- What do you think would be helpful to support "caregivers" to do the work they are doing?
- Some service providers in this context find themselves doing a lot of the work that family members and friends often do. What is your experience with that? What needs to happen to support these kinds of service provider/caregivers?

We have come to the end of the interview but I'd like to end by asking you:

- Is there something that you expected me to ask you that I didn't?
- Was there anything else you wanted to tell me that you didn't get the opportunity to?
- If I have some follow up questions are you ok with me coming back to you?

Complete demographic questions – During the interview, the person may answer some of these questions (e.g., role, organization) so you can track as you go.

Demographic Questions

1. What is your age in years?

☐ Please specify: _____

☐ I prefer not to answer

2. How do you currently describe your gender?
☐ Please specify: _____
☐ I prefer not to answer

3. How would you describe your racial or ethnic group?
☐ Please specify: _____
☐ I prefer not to answer
☐ Unknown

4. Which of the following best describes your highest level of education?
☐ Less than high school
☐ High school diploma or equivalent (e.g., GED)
☐ Some college, no degree
☐ Vocational or technical certificate (e.g., HVAC, automotive technology, cosmetology)
☐ Associate degree (e.g., AA, AS)
☐ Bachelor's degree (e.g., BA, BS)
☐ Postgraduate certificate or diploma
☐ Master's degree (e.g., MA, MS, MEd, MSW, MBA)
☐ Professional degree (e.g., MD, DDS, DVM, LLB, JD)
☐ Doctorate degree (e.g., PhD, EdD)
☐ Prefer not to answer

5. What is your current professional role? _____
6. How many years have you worked in your current position? _____
7. How many hours a week on average do you work? If you have multiple jobs, please add up the hours for all your jobs. Hours per week: _____

8. Do you have formal training/education in palliative care?
☐ Yes
☐ No
☐ Prefer not to answer
☐
9. Have you participated in workshops or training in any of the following? [select all that apply]
☐ Trauma and violence- informed care
☐ Cultural safety/ anti-racism
☐ Harm reduction/substance use health
☐ Prefer not to answer
☐ Other- please specify: _____

Interview Reflections

Date and Time:

Location:

Participant Code:

Section 1: Description of activity

Summary: Summarize your initial impressions of the interview.

Prompt: "What were the 5 most important things that came out of this interview?"

_____

Section 2: Reflections

List any personal assumptions or meanings you can identify

_____

Section 3: Emerging questions/analyses

Potential lines of inquiry, theories, common narratives

_____

Section 4: Future action

Including further contacts, potential stakeholders to include, revisions to the guide or process, issues

_____