



# Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life

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## ABSTRACT

The process of dying pronounces inequities, particularly for structurally vulnerable populations. Extending recent health geography research, we critically explore how the ‘places’ of formal healthcare settings shape experiences of, and access to, palliative care for the structurally vulnerable (e.g., homeless, substance users). Drawing on 30 months of ethnographic data, thematic findings reveal how symbolic, aesthetic, and physical elements of formal healthcare ‘places’ intersect with social relations of power to produce, reinforce, and amplify structural vulnerability and thus, inequities in access to care. Such knowledge may inform decision-makers on ways to enhance equitable access to palliative care for some of societies’ most vulnerable population groups.

## 1. Introduction

Care at the end-of-life takes place across a range of settings, from formal institutional spaces of hospitals, clinics, physician offices, to hospices, and informal spaces like the home. The phrase ‘takes place’ implies the occurrence of care activities, but also the literal ways in which one occupies a place in a specific setting, social hierarchy, or system (Kearns, 2018). Conceived in this way, place undoubtedly plays a significant role in shaping experiences of, and access to end-of-life care, resulting in diverse populations experiencing various care settings in different ways.

While all people at the end-of-life experience vulnerability due to their expressed state of needing care (Bondi, 2008), this vulnerability is significantly amplified for those who also experience ‘structural vulnerability’. Viewed through an intersectional lens (Bauer, 2014; Crenshaw, 1994; Hulko, 2009; Hankivsky and Cormier, 2010), structurally vulnerable populations are characterized in this study as those

living in poverty and experiencing various levels of homelessness, as well as multiple forms of social isolation, racism, ongoing trauma and violence, stigma associated with mental health issues or cognitive impairments, behavioural issues, previous or ongoing substance use, experience with the criminal justice system, and (dis)ability and/or mobility challenges (removed for peer review). Structural vulnerability is produced through one’s lower position in hierarchical social orders which, as a result, constrain choices and opportunities while amplifying vulnerability to risk, harm, and negative health outcomes (Mcneil et al., 2015; Quesada et al., 2011). Those who experience structural vulnerability and are dying, therefore, may be considered ‘doubly vulnerable’ (Reimer-Kirkham et al., 2016) and will likely, from this situated ‘place-in-the-world’, have unique experiences of the places where their end-of-life care occurs.

In this analysis, we apply the critical theory of intersectionality to elicit some of the complex ways that ‘place’ intersects with social relations of power to produce and reinforce inequitable access to care at

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the end-of-life for those experiencing structural vulnerability (Commission on Social Determinants of Health, 2008; Varcoe et al., 2014; Reimer-Kirkham et al., 2016). Specifically, we aim to explore, through the lens of therapeutic landscapes (Gesler, 1992; Williams, 2010), how formal healthcare settings are experienced by those living with structural vulnerability on a palliative trajectory. The purpose is to gain a more nuanced understanding regarding how such places shape access to care for structurally vulnerable populations. By drawing on 30 months of ethnographic data collected in Victoria, British Columbia, Canada, the findings of this analysis centre on structurally vulnerable participants' perspectives and place-based experiential knowledge of healthcare environments. Such knowledge holds the potential to inform decision-makers on ways that may directly impact policy, practice, and systems-level changes (Andrews and Moon, 2005) to enhance equitable access to palliative care for some of societies' most vulnerable population groups.

### 1.1. Access to care: dying within structurally vulnerable conditions

The process of dying pronounces inequities (Reimer-Kirkham et al., 2016; Stienstra and Chochinov, 2012; Parliamentary Committee on Palliative and Compassionate Care, 2011). As intersectional scholars remind us, ways of life, income status, geography, education, culture, ethnicity, sex, gender, among other axes of diversity, all coalesce to shape not only one's everyday lived reality (Hancock, 2007; Hooks, 1990; Hankivsky et al., 2011), but also access to, and experiences of, palliative and end-of-life care<sup>1</sup> (Giesbrecht, 2012). Palliative care is defined by the World Health Organization (WHO) (2011) as whole-person care that aims to improve the quality of life of patients and their families facing life-threatening illness. This care is done through the prevention and relief of suffering by means of early identification, efficient assessments and the treatment of pain, and other physical, psychosocial, and spiritual problems. While many in the global community have sought to identify palliative care as a universal human right (Brennen, 2007; Henteleff et al., 2011; Knaul et al., 2017), access to such care remains highly inequitable (Care Quality Commission, 2016; World Health Organization and Worldwide Palliative Care Alliance, 2014; Klinger et al., 2014). These inequities are partly the result of the way in which programs, policies, and healthcare spaces and places have been designed, which target and cater to particular population groups. Such designs reflect and reinforce inequities associated with assumed ideals of who is in need of such services and where such care takes place (Stienstra and Chochinov, 2012; Browne et al., 2012).

In the palliative context, access to care focuses on the degrees to which people with life-limiting conditions are able to obtain the services and supports required to maintain a quality of life, through the management of pain and suffering, until the moment of death (World Health Organization and Worldwide Palliative Care Alliance, 2014). Traditionally, access to care has been viewed spatially with much focus on the physical distance between fixed care sites and places of residence (Kearns, 2018). Today, however, accessibility is understood as being dynamic, complex, multi-faceted, and multi-dimensional, including perceptions of service quality, temporal availability, affordability, continuity, connectivity, and acceptability (Penchansky and Thomas, 1981; Goddard and Smith, 2001; Gulliford et al., 2002). The most nuanced is arguably the latter, acceptability, as it captures the extent to which a client is comfortable with the more immutable characteristics of the provider, and vice versa (Penchansky and Thomas, 1981). These characteristics include the age, gender, social class, and ethnicity of the

<sup>1</sup> Often used synonymously, the terms palliative and end-of-life refer to care provided at differing points in one's trajectory. Palliative refers to care provided to anyone facing a life-limiting conditions, while end-of-life refers to care for those who are deemed terminal and predicted to die in the foreseeable near future. World Health Organization (2011), Fowler and Hammer (2013).

provider (and client), as well as diagnosis (Penchansky and Thomas, 1981). For example, perceptions of (in)acceptability have been found to result in care being postponed or completely avoided by those in need if the services offered are deemed 'culturally unsafe', even if they are located within close proximity (Wepa, 2015; Grewal et al., 2004). While research with Indigenous peoples and other cultural minority groups has been the primary focus when exploring care 'acceptability' (Wepa, 2015; Joseph and Phillips, 1984), perceptions of safety and acceptance of other population groups, particularly the structurally vulnerable, remain largely unexplored in the context of palliative care. Furthermore, reaching beyond client and provider characteristics, little is known regarding how the physical and social 'place' of healthcare settings influence care acceptability, and thus, access to care.

Despite death being a universal experience, the vast majority of those currently accessing palliative care across much of the Global North fit into particular sociodemographic and economic profiles (e.g., diagnosed with cancer, from majority cultural and religious groups, mid- to higher-income levels, stably housed, socially connected) (Giesbrecht, 2012; Mcneil et al., 2012a; Care Quality Commission, 2016; Stajduhar, 2011). The experiences of other population groups, particularly the structurally vulnerable, are largely invisible, resulting in their needs remaining unaddressed (Webb, 2015; Mcneil et al., 2012b; Mac Williams et al., 2014; Mcneil and Guirguis-Younger, 2012; Schulman et al., 2017). Ko et al. (2015) have found that homeless older adults avoided seeking medical care at the end-of-life out of fear of discrimination and not being deemed worthy by providers to receive life sustaining treatments, as well as negative emotions associated with end-of-life planning due to personal experiences of trauma. Other studies have indicated that homeless populations have fears of dying anonymously or undiscovered (Song et al., 2007; Song et al., 2008; Hudson et al., 2017; Shulman et al., 2018), while their experiences of death is often not 'ideal', such as being alone in acute care settings, shelters or transitional housing, or in alleys, streets, or vehicles (Cagle, 2009; Jackson and Sessums, 2007; Song et al., 2008).

### 1.2. The 'places' of end-of-life care and those experiencing structural vulnerability

The place where end-of-life care occurs is the result of complex and dynamic political and social processes that influence rights and responsibilities (Milligan and Power, 2010; Dyck, 2005). Across the Global North, neoliberal policies and resulting healthcare reforms have increasingly shifted the responsibility of palliative care from the state to voluntary and informal sectors (Skinner and Rosenberg, 2005), which directs 'where' care takes place. Namely, moving care from institutional settings into the community, particularly the home. Such shifts, however, exclude a significant proportion of the population who do not have a safe and secure home, thus, reinforcing a model of care that is highly inaccessible for this group. Within Canada, 35,000 are estimated to be homeless each night, with at least 235,000 Canadians experiencing homelessness (i.e., unsheltered; emergency sheltered; and provisionally accommodated homelessness) per year (Gaetz et al., 2014). Concurrently, Canadian palliative care policy is largely directed towards increasing supports for 'home deaths' (Giesbrecht, 2012; Carstairs and Macdonald, 2011; Canadian Hospice Palliative Care Association, 2012). The outcome is that those who are dying and experiencing structural vulnerability, particularly homelessness, have increasingly limited options in where they can access palliative care. This restricted access results in their care often occurring within institutionalized public healthcare settings, such as hospitals, physician clinics/offices, and inpatient palliative care units.

Although much diversity exists within homeless populations (e.g., race, ethnicity, sex, gender, mental health status, ability, among others), as a whole, they have increasingly been 'denied a place' across public spaces (Mitchell, 1995, 2003). Homeless peoples often experience spatial exclusion and a 'restricted right' to the public spaces in

which they must live (Mitchell, 1995, 2003; Blomley, 2004). In efforts to improve capital investments, via an emphasis on ‘livability’ and ‘quality of life’, city politicians and managers have turned to legal remedies in order to ‘cleanse’ public spaces where homeless people are (Bergamaschi et al., 2014). Such strategies include regulating behaviours (e.g., outlawing public drinking, sleeping on benches, etc.) and deterrence tools (e.g., anti-homeless benches, fences, signs, etc.) (Doherty et al., 2008). Those in favor of controls and deterrents justify such measures through stereotypes of disease and disorder, labelling homeless people as contagious, inferior, and deserving of regulations in an attempt to protect the wider public (Amster, 2003). Although this spatial exclusion has been found to persist across many urban public spaces, there exists little research that specifically explores how the places of public, formal healthcare sites are experienced by structurally vulnerable populations at the end-of-life and how these places impact access to care. Furthermore, few studies apply an intersectional lens to research with homeless populations to consider how differing lived realities (e.g., race/ethnicity; mental health; indigeneity, among others) may also shape experiences of healthcare places and spaces.

## 2. Methods

This analysis is based upon data collected for a larger ethnographic study that, through the theoretical perspectives of equity and social justice, aims to explore access to care for those who are in need of palliative care and experiencing structural vulnerability (for more details, see removed for peer review). Ethnographic methodologies focus on qualitatively exploring the nature of particular social phenomena in the environment where they occur (Savage, 2000). Ethnographers employing critical perspectives aim to generate knowledge that leads to social change by focusing on observing and understanding how social structures, processes, and ideologies coalesce to constrain peoples’ lives (Thomas, 2003). Ethics approval for the study was obtained from the local University and Health Authority Research Ethics Sub-Committee.

### 2.1. Data Collection

The study took place in Victoria, British Columbia, Canada. Participants were sought from three groups: (1) people experiencing structural vulnerability who were on a palliative trajectory; (2) their support persons (e.g., ‘street family’); and (3) their formal service providers (e.g., housing workers, medical professionals).

Recruitment was done in collaboration with two community-based organizations who work closely with structurally vulnerable populations. Health and social care service providers were recruited from these organizations as participants, and after providing consent, were invited to recruit participants experiencing structural vulnerabilities who were deemed to be on a palliative trajectory (i.e., high risk of dying within a one-year time-frame). To capture maximum variation among these participants, diverse characteristics were purposely sought (e.g., disease, living situation, mental health and/or substance use, gender, age, ethnicity). Some had support persons (e.g., family, friends, street family) who provided them with various levels of care and they were also invited to participate (removed for peer review).

Overall, the study included 25 participants experiencing structural vulnerability, 25 informal support persons, and 69 formal service providers. Characteristics of participants experiencing structural vulnerability are summarized in Table 1. While these participants resided in various settings, they were all characterized as homeless or at risk of homelessness (Canadian Observatory on Homelessness, 2012). Their support persons generally shared similar demographics (e.g., unstable housing, low income) and most were structurally vulnerable themselves. Service providers ranged in occupational diversity, including: outreach/support workers ( $n = 16$ ); nurses ( $n = 13$ ); physicians ( $n = 15$ ); housing workers ( $n = 7$ ); managers/coordinators ( $n = 4$ ); counsellors ( $n = 5$ ); and others (chaplains, community relations

**Table 1**  
Structurally vulnerable participants’ characteristics ( $n = 25$ ).

Characteristic	Number of participants
Gender	16 men 9 women
Age range	19–81 years
Mental illness	7 yes, self-reported 7 yes, identified by health provider (including undiagnosed, but suspected) 11 no
Self-reported use of illegal drugs	12 yes 13 no
Housing status	11 social or public housing 8 market housing (with roommates/financial supplements) 2 transitional housing 4 homeless (e.g., shelter, boat, hospital, etc.)
Race/ethnicity	13 White/European settler 8 Indigenous 1 African Canadian 3 did not respond
Sexual orientation	20 heterosexual 2 LGBTQ 3 did not respond
Level of education	2 some elementary 2 completed middle school 4 some high school 6 completed high school 4 some college (including trade school) 3 completed college or university 4 did not know/respond
Marital status	9 divorced or separated 8 single 3 married/common law 2 widowed 3 did not respond
Substance use <sup>a</sup>	16 tobacco/alcohol 11 opioids 10 cannabis 3 powder cocaine
Died during the research process	13 yes 12 no

<sup>a</sup> The number of participants captured here includes both single and multiple users as it is based upon the interview question of: “In the last 30 days, have you used any of the following substances?” During observations with structurally vulnerable participants, it was found that many under-reported substance use, and as such, participants’ responses to this question were adjusted accordingly.

officers, etc.,  $n = 9$ ).

Data collection involved repeated participant observation with structurally vulnerable participants over 30 months, resulting in approximately 300 h of fieldwork. The relationship between the researchers collecting data and participants was not pre-existing; yet, all researchers conducting data collection held experience working with structurally vulnerable populations. Participants experiencing structural vulnerability were provided with either a \$20 CAD cash honorarium or the financial equivalent in food and/or nutritional supplements for each observation. Observations were conducted in homes, shelters, transitional housing units, clinics, physician offices, hospitals, palliative care units, community-based service centres, and outdoors such as in parks or on the street. Observations were made around-the-clock and throughout the week without restrictions. The goal of observations was to document access to healthcare services for those experiencing structural vulnerability on a palliative trajectory. Observational data were supplemented with in-depth interviews, which clarified and validated what was being observed. These interview questions were context specific and included asking participants, for example, to describe the healthcare interaction that was just observed and how they felt about it or to describe their decision-making process regarding how, where, and when they chose to access particular care. All interviews ( $n = 19$  structurally vulnerable participants;  $n = 16$

support persons; and  $n = 23$  service providers) were digitally recorded, transcribed verbatim, and together with observational fieldnotes, entered into NVivo™ for analysis.

## 2.2. Analysis

Analysis of the data was conducted by the entire research team who met repeatedly throughout the data collection process to identify emerging themes and issues to consider for further investigation. The constant comparative technique was used, which involves data collection and analysis occurring concurrently (Stern, 2008). Broad themes were identified by the research team, and upon reaching consensus, coding of the data began. Coding of the data was conducted by a team of three researchers, two of whom were also involved with data collection. Data were coded and recoded using an inductive process of organization, whereby incidents or themes were compared to other incidents or themes during the process of coding. Intersectionality was the theoretical positioning used throughout the process of coding, which began with open coding to develop broad categories that were then refined and recoded (e.g., barriers to care; facilitators to care; place-based experiences) (Stern, 2008; Hammersley and Atkinson, 1995). Intersectionality is concerned with simultaneous interactions between aspects of social difference and identity (e.g., race/ethnicity, socio-economic status, mental health, disability, etc.), and forms of systemic oppression (e.g., racism, classism, ableism, etc.) at macro and micro levels in ways that are complex and interdependent (Hankivsky et al., 2011). Such equity-based approaches aim to critically examine whether the distribution of resources or outcomes of various social processes is fair among different groups of people, while the concept of social justice challenges inequities at their source by critically examining how complex social and power relations contribute to the development of structural inequities (Commission on Social Determinants of Health, 2008; Varcoe et al., 2014; Reimer-Kirkham et al., 2016).

This analysis draws on data initially coded into the broad theme of ‘place-based experiences’, which captured how places, in the physical and social sense, shaped participants’ experiences of care. Using this data, a more refined thematic analysis unveiled which healthcare settings were accessed by participants and how these places were experienced in the context of end-of-life. The lens of ‘therapeutic landscapes’ (Gesler, 1992; Williams, 2010) was applied at this point of the analytic process, which offered a valuable lens through which care spaces/places were examined, particularly if/how they contributed towards, or impeded, therapeutic care experiences at the end-of-life for structurally vulnerable populations. Again, throughout this process, multiple research team meetings took place to review developing ‘place-based’ coding schemes and emerging themes, which enhanced rigor via investigator triangulation. To ensure anonymity, all participants have been assigned pseudonyms.

## 3. Findings

Overall, it was found that participants received the majority of their care in the public spaces of formal healthcare settings. As such, these formal places became the focus of the current analysis. It is important to emphasize that although we focus on formal care sites, the social and physical boundaries surrounding these spaces are not hermetic, static, and fixed, but rather are porous, with ‘informal’ often permeating into ‘formal’ environments, and vice versa (Milligan and Power, 2010; Andrews, 2003; Yantzi and Rosenberg, 2008).

The formal care settings accessed by our participants were primarily hospitals, physician clinics/ offices, and inpatient palliative care units. Although the inpatient palliative care units were physically located within hospital buildings, the environment and care provided differed in its orientation by following a palliative philosophy and approach to care. Experiences of these settings fell into three broad place-based

themes: (1) symbolic representation; (2) site aesthetics and ambiance; and (3) site location and issues of mobility. While we categorize findings into three separate themes, the experiences presented are not isolated events, but rather are highly relational and interconnected. For example, experiences of getting to a care site may affect one’s mood and shape how one experiences the aesthetics of a place once they arrive. Also, the symbolic representation of a care site may similarly affect experiences of the ambient environment. In the following sub-sections, we provide details on each of these thematic findings.

### 3.1. Power, identity, and place: meanings and symbolic representations

This thematic finding focuses on participants’ experiences of the symbolic dimension of formal care spaces, which are permeated by diffuse power relations. As such, this finding examines those broader structural forces that shape participants’ lived realities and, in turn, how formal care spaces are symbolically interpreted and perceived. Overall, the symbolic representations of these care spaces included the inflexible and oppressive systems of institutional control, paternalistic medical power, places of ‘no return’, and spaces of hygienic ‘sanitation/purification’.

Symbolic representations of hospital settings, particularly, were often found in the data. For many participants, hospitals symbolized the inflexible and oppressive systems of institutional control. It is also from within the context of colonialism, racism, and the Canadian residential school system that the hospital was symbolically perceived by many Indigenous participants. Residential schools for Indigenous people in Canada date back to the 1870s with the last school closing in 1996. Over 130 residential schools were located across the country, which were government-funded and church-run, and set up to eliminate parental involvement in the intellectual, cultural, and spiritual development of Indigenous children (Truth and Reconciliation Commission of Canada, 2016). Lewis, an Indigenous man with end-stage adrenal carcinoma, was characterized by providers as being firmly “anti-hospital”. It was stated by his support worker that Lewis had:

*“a lot of distrust in the bureaucratic systems that we have in place. So he had a lot of distrust in things like the hospital, quite understandably. He was very resistant to going to the hospital. If he could avoid that, he would at all costs.”*

Linda, an Indigenous woman with end-stage cancer, similarly avoided hospitals. From a young age she had survived a foster care system, sexual and physical abuse, residential school, and had a severe distrust of the medical system. Due to colonial and personal histories of surviving systemic violence, the representation of hospitals for Indigenous participants often triggered traumatic experiences. A service provider described in an interview the experiences of another client, explaining that:

*“...because he was institutionalized as a child and abused, he has great fear of being in an institution, even in a hospital. It just, it feels like an institution. People are in uniform of a sort, it’s that sort of regimented atmosphere and it just, that provides triggers and he just feels like he can’t stay.”*

This representation of hospitals resulted in these participants avoiding formal care until only months/weeks before death, and only once their pain became unbearable.

Participants also avoided physician clinics/offices as these spaces, and those who work within them, were perceived to represent paternalistic medical power. The physicians/nurses working within these care settings were often interpreted as symbolic personifications of the western medical system, who perform required health and medical services to those in need, and as a result, are rewarded with high social prestige, status, and power. For participants, entering these formal, orderly environments, where care from the high ranking ‘pillars’ of society (e.g., physicians; specialists) are accessed, often resulted in

unease, anxiety, frustration, and even anger. For example, Julie, a case manager, described how Lewis:

*“...very much shuts down in those very stiff kind of environments like that. So I think he’d probably have doctors telling him things and he just would close off. Like I went to a few medical appointments where he just was like, ‘Yeah, I’m done listening to this’ and just got up and walked out and would say to me, ‘You finish this.’ And would just leave.”*

Paternalistic medical power also influenced the information participants chose to disclose, particularly behaviours such as substance use. For example, Carl, who was living with pancreatitis, described meeting with a specialist and how he did not disclose that he was actively using substances, despite his knowledge that it affected his health and treatment:

*“If they’d have known that I was using, oh yeah, it [the health-care interaction] would have been totally different...They would’ve probably shuffled me out the door and said ‘fuck it’, you know”.*

Participants were acutely aware of this power imbalance, and as a result, often exerted their own power by choosing either not to seek care, or by not complying with the treatment regimen. The representation of paternalistic medical power attributed to these care settings exacerbating participants’ sense mistrust, exclusion, and vulnerability.

For many participants, palliative care units were generally perceived as spaces of ‘no return’, evoking avoidance and fear. While this representation is not unique to our participant group, it did result in a relatively greater barrier in access due to participants’ histories and lived contexts. For example, observational data showed that because participants’ days were continuously spent ‘surviving’ (e.g., finding food/place to sleep), with priorities focused on addressing immediate concerns, they experienced grave difficulties in not only projecting into and/or planning for the future, but also in acknowledging and/or recognizing that they were approaching death (For more details, see removed for peer review). As a result, palliative care units, which symbolized an inevitable end (at some point in the unforeseeable future) to a life they had continuously been fighting to live, was not viewed as a pertinent place to access care.

Rooted in the traditional, western, highly-medicalized healthcare culture, hospitals, physician clinics/offices, and palliative care units have come to represent spaces of hygienic ‘sanitation/purification’. Such representations, however, result in an underlying and impulsive desire or need to ‘de-contaminate’ or rid these environments of ‘un-sanitary’ or ‘impure’ things and people. This representation is therefore based on divisive processes of ‘othering’, which is reinforced by stigmatization, criminalization, and classism, and perpetuates the categorization of ‘dirty’ people (e.g., those with mental illness, who are homeless, with unmanaged drug addictions) as not belonging. Rufus complained during an interview about the signage that often appears in healthcare settings and how the posting of such ‘zero-tolerance’ signs, which demand subservient behaviour, evoked irritation and anger:

*“I certainly notice it at the [Institute] and I’ve noticed it at hospitals and this type of thing, is these zero-tolerance signs... and you get these signs all over the place, all over the [Institute]. And I consider it offensive... it’s sort of like they demand docility from their clients.”*

The posting of such signs signal a powerful symbolic message to Rufus that is interpreted as ‘patronizing’ and ‘othering’, reminding Rufus of, and ensuring he stays, in his ‘place’. For others, it was observed that the outcomes of mental health issues, non-conventional behaviour, or use of illicit drugs led to their medical charts being permanently marked with a purple dot, indicating to all who see that they are ‘dangerous’. Participants who raised their voices to staff were physically sectioned in the hospital and moved to medical rooms on different floors. Thus, the representation of formal care spaces being ‘orderly’, ‘sanitized’, and ‘pure’ resulted in the creation of boundaries

between those who embody certain societal ideals (pure) and those who do not (impure). These divisive practices of ‘othering’, including patient labelling and categorization, reinforce the stigmatic assumptions that underlie many policies and practices through the guise of risk/safety discourse.

### 3.2. Inside the walls: aesthetics and ambiance

This thematic finding focuses on personal interactions between participants and the materiality of the physical/social environment within formal care settings. While some physical spaces evoked cold, austere institutional experiences, others were found to be more home-like, warm, and accommodating. Overall, medical power was found to emanate strongly from the physical and social aspects of all these spaces, particularly through their design, the distancing of professionals from elements of participants’ experiences, and the act of surveillance, all of which contributed to an increased sense of social exclusion, disempowerment, and vulnerability.

Although hospitals, physician clinics/offices, and inpatient palliative care units varied dramatically aesthetically, and considering that each participant inevitably experienced these places differently, a common pattern of experience was found. Generally, hospital aesthetics were perceived as austere and institutional with sparse décor, beeping medical equipment, and people dressed in uniform, while the social ambiance was perceived as hierarchical, cold, and impersonal. Although only a minority of participants accessed inpatient palliative care units for care ( $n = 7$ ), of those who did, the physical aesthetic was often viewed as being much more pleasant. This was because of more home-like furnishings such as upholstered chairs and home-made quilts on beds. Patients of these units also had access to a smoking room and a rooftop garden. Furthermore, the social ambiance was perceived as being relatively more personal, compassionate, and accommodating. While these experiences are again not unique to our participant group, they are particularly pronounced for them due to their previous life experiences and current lived contexts, which promote an amplified sensitivity to the ways in which power relations emanate from their surrounding environment, including attempts to control and/or ‘other’.

Although hospital and physician clinic/office settings provided positive experiences for a few, this was not the case for the majority of participants. In hospital, participants complained about the institutional feel of “stuffy air” and “smells”, or the constant “noise of toilets flushing”. The architecture of hospital buildings also evoked negative experiences. For example, during observations with Wilfred, a man living with advanced dementia, a researcher described that they were:

*“Immediately struck by the institutional feel of the building. It was large and consisted of multiple square structures, and there were very few windows visible when I pulled up... On the right was a chain link fence... The doors themselves were institutional in appearance (metal and glass) and were locked.”*

These “institutional” aesthetics contributed towards reinforcing the symbolic interpretation of these places and magnifying participants’ perceptions of being ‘subjected to the system’, including associated experiences of disempowerment, and increased levels of stress, anxiety, fear, and trauma.

Various sets of social dynamics, together with aesthetics, contribute toward a place’s ambiance. As mentioned previously, medical power was pervasive and visible to participants. This medical power was interpreted through the physical layout and design of these spaces. For example, the existence of waiting rooms in physician clinics/offices, whereby patients/clients were expected to wait, often for long, extended periods of time, until the physician was ready for them. Such designs create a distance between physicians and many aspects of patients’/clients’ experiences. Once in the “sterile” office, interactions were colored with medical jargon, reinforcing existing power relations and the sense of exclusion. For example, Julie described how during a

meeting, Lewis'

*"oncologist who... talked very medical lingo and left [Lewis], like glazed. I was like, 'He's not understanding a word that you're saying right now.' It was the least accessible language possible!"*

It was observed that during these interactions that participants were often not at ease and rarely asked questions, often leaving without their concerns addressed and with little understandings of their diagnoses/prognoses.

In the hospital setting, whereby all elements of participants' daily lives were perceived to be regulated and monitored, medical power was significantly persistent. During an observation, Wilfred shared that the hospital felt like *"being in prison"*. Amber shared similar sentiments, explaining in an interview that:

*"I wake up and there's a bed alarm on me and so I get up to go to the bathroom and they instantly know I'm awake and moving and off my bed... It starts dinging and then all the nurses are there... Not letting me go to the bathroom so I'm not going to go do drugs."*

Other participants similarly commented on how they felt they were constantly under surveillance and not allowed to use the bathrooms, go outdoors to smoke, and were restricted from having visitors. As a result, many participants detested the hospital, with some leaving as soon as they were able and before they were formally discharged. As Amber described: *"Basically every time I go to the hospital, I don't discharge, I just leave when I decide I'm done... if they didn't let me leave, it's... Prison break, but hospital break."* Furthermore, few providers took the time to inform participants of, and ensure they understood, why they were being 'kept/held' in the hospital and for how long they would likely have to stay. This power-laden ambiance resulted in an overall sense of disempowerment, imprisonment, and increased sense of social exclusion for participants.

### 3.3. Travelling to and from: Issues of mobility and the location of care sites

As one approaches end-of-life, the need for and frequency of formal healthcare intensifies, while at the same time mobility diminishes. Intersecting with structural vulnerability, this context resulted in significant challenges for our participants, who without secure housing, were left with little option but to travel in order to access care with limited material resources and social support. Factors shaping their experience included the distance to care sites, the financial cost of transportation, and transportation routes in the context of declining physical capacity and in some cases, cognitive impairments. Such inequities were found to reinforce participants' socio-spatial marginalization and magnify the barriers and stressors associated with physically accessing needed care.

The most common barrier raised by participants was the financial cost of transportation to and from appointments. Without access to privately owned vehicles, participants relied on costly public transportation (e.g., taxi, bus). George, who was living with advanced cancer and kidney failure, shared:

*"They built that new hospital way out in the boonies and it costs you \$50 or \$60 [taxi fare] to get in there and people in my stage of life and situation don't have that kind of money... Why didn't they build the fuckin' hospital in town where it's more accessible, that people could either walk or take the bus?!"*

During the study, George was required to travel to this hospital four times, resulting in severe anxiety, stress, and financial hardship. George also experienced challenges in physically accessing his pharmacy and suffered for extended periods of time without pain medications. George's example demonstrates how social isolation and poverty, coupled with life-limiting illness, function to produce socio-spatial dynamics that exacerbate suffering and inequities in accessing care.

While the distance and cost to reach some care sites was

problematic, it was also those healthcare facilities located nearby that posed problems for participants. Rufus had severe mobility issues and required a walker. He shared that there was no direct bus-route between where he resided and his physician's clinic, which meant he had to transfer buses multiple times. So Rufus took taxis instead, costing him approximately \$20 CAD each way; a substantial amount for someone living in poverty and who, due to his multiple comorbidities, had numerous ongoing medical appointments and procedures. Other participants chose to take public transportation, such as busses, despite the cost and their severe pain or mobility challenges, demonstrating how life-limiting illness coupled with structural vulnerability produces undue suffering. Betty, a woman living with advanced cancer, fell backwards when exiting a bus with her walker and fractured her hip, significantly intensifying her pain and negatively affecting her quality of life. Participants with mobility devices, such as walkers, commonly complained of others riding public transport not respecting designated handicapped seats, resulting in them having to exert even greater energy and effort to claim their rights to these spaces and ride safely to their medical appointments. These findings highlight the challenges faced when participants are left to navigate the city's largely able-ist terrain in order to access care.

While all participants had mobility challenges due to their life-limiting illnesses, it was those with mental health and/or cognitive issues who faced the greatest obstacles travelling to access end-of-life care. These participants experienced major challenges navigating unfamiliar spaces, following maps, and locating particular addresses, which resulted in many simply giving up or not even attempting to go to their medical appointments. During observations it was apparent that Wilfred, who was living with dementia among other mental illnesses, often became confused and lost: *"He asked me [researcher] where we were and I said at his apartment and pointed to his front door."* Expecting Wilfred to find his own way to medical appointments or to coordinate his care and remember his appointments is simply not feasible. Overall, these findings demonstrate how life-limiting illness and restricted mobility/mental capacity exacerbate existing structural vulnerability, reinforced by structural arrangements (e.g., transportation routes; taxi costs; limited financial resources). Furthermore, the amount of work participants did prior to leaving, such as searching for and planning transportation options and routes, as well as the energy and inequitable suffering that occurred during travel, increased their sense of frustration, marginalization, and sense of 'place' within the broader social/physical landscape.

## 4. Discussion: understanding the intersection of 'place', end-of-life care, and structural vulnerability

Since its inception, health geography has been concerned with questions of access to care, power, and inequity, particularly through emphasis on broader notions of wellbeing, giving voice to those who too often are silenced, and valuing experiential knowledge derived from those living with various health issues/concerns (Dyck and Moss, 2002; Brown, 1995; Kearns, 1993; Conradson, 2003a). By applying an intersectional lens, the findings from this analysis build upon this body of research, reminding us that experiences of, feelings towards, and agency in healthcare settings are dynamic, multidimensional, and complexly shaped by both the characteristics of 'places' themselves and the situated 'place-in-the-world'/characteristics of the diverse array of populations and individuals who frequent them (Gesler, 1999; Poland et al., 2005; Andrews, 2011; Cummins et al., 2007; Hancock, 2007; Hankivsky et al., 2011). Uniquely, however, our findings offer valuable experiential knowledge regarding the power imbued within healthcare settings and the ways in which these places serve to produce, reinforce, and/or amplify structural vulnerability and thus, inequitable access to end-of-life care for particular population groups.

Although substantial geographic research has given attention to structurally vulnerable populations, the 'place' of focus in these

analyses tend to be on care settings in the community and street (e.g., drop-in centres, community-based recovery sites) (Conradson, 2003b; Conradson and Moon, 2009; Wilton and DeVerteuil, 2006; Wilson et al., 2014). Thus, our findings inform health geography literature by eliciting structurally vulnerable peoples' place-based experiences of accessing care within public/formal healthcare settings, and particularly how these places, including those traversed enroute, are often symbolically and aesthetically experienced as unacceptable and anti-therapeutic. Penchansky and Thomas's (1981) concept of 'acceptability' is highly apparent in our findings, revealing both those tangible and intangible place-based barriers associated with experiential aspects of public healthcare settings. Building upon the concept of therapeutic landscapes (Williams, 2010; Gesler, 1992), our findings demonstrate how the anti-therapeutic qualities of these settings served to influence structurally vulnerable populations' willingness/readiness to access/utilize existing services. Furthermore, the findings build upon existing literature regarding the cultural dynamics of healthcare settings by demonstrating the various ways they can be 'read' and decoded, by diverse population groups, in order to have their meaning (symbolic or otherwise) constructed (Kearns and Collins, 2010; Gesler, 1992; Andrews, 2011; Kearns and Barnett, 1997).

Importantly, our findings divulge how those experiencing structural vulnerability at the end-of-life simply do not 'fit' into public/formal healthcare environments, yet have *no place else to go* to access needed care. While it is recognized that such 'placelessness' is increasingly experienced by the homeless across many urban landscapes (Doherty et al., 2008; Mitchell, 2003; Masuda and Bookman, 2016), our findings emphasize how this denied 'place-in-the-world' becomes ever-more pronounced as one advances across the lifecourse, becomes increasingly vulnerable, and approaches the end-of-life. Such spatial exclusion was found to produce adverse symbolic, political, cultural, physical, emotional, and social outcomes that were not conducive to quality palliative care. Many participants lived their entire lives outside the mainstream health system; making them live their final days in that system only added to their suffering (Collier, 2011). Thus, these anti-therapeutic places of healthcare were found to amplify discomfort, fear, anxiety, and harm (Andrews et al., 2012), which resulted in disproportionate and undue hardship.

The place-based experiential knowledge offered within the findings hold the potential to inform decision-makers on ways to directly impact policy, practice, and systems-level changes (Andrews and Moon, 2005), particularly on ways to enhance access to, and the quality of, palliative care to structurally vulnerable populations. Considering participants' generally negative place-based experiences of public/formal healthcare settings, and echoing promising practices raised elsewhere (Henry et al., 2017; Huynh et al., 2015; Centre for Urban Health Solutions Survey Research Unit, 2017), our findings suggest that palliative care must become both more flexible and mobile. This suggests that palliative care should be provided in a *variety* of settings, particularly those deemed acceptable and safe by structurally vulnerable populations.

Palliative care services need to be offered in environments that reach beyond formal healthcare settings to meet clients 'where they are at'. Such care will require the mobilization of services into those places considered safe and therapeutic for those who have lived on the street for extended periods of time, such as shelters, drop-in centres, and/or the street (Centre for Urban Health Solutions Survey Research Unit, 2017; Henry et al., 2017; Abelson and Giacomini, 2003; Palepu et al., 2013; Shulman et al., 2018; Bridgeman, 1999). The implementation of shelter-based approaches that employ harm reduction strategies and/or facilitate partnerships between palliative services and existing social services, such as shelters, drop-in meal programs, and harm reduction sites appear highly promising (Centre for Urban Health Solutions Survey Research Unit, 2017; Inner City Health Associates, 2016). Furthermore, what may be required is a re-visioning of what 'home', in the context of home-based care, means in order to disrupt harmful assumptions that underlie current Canadian palliative care policy (Centre

for Urban Health Solutions Survey Research Unit, 2017; Inner City Health Associates, 2016; Huynh et al., 2015). Increasing flexibility (and knowledge/training of providers) surrounding what is considered a 'safe work' environment is also necessary to enhance equitable palliative care to structurally vulnerable populations. Expecting those who are dying and experiencing structural vulnerability to seek out and coordinate their own palliative care, often with limited social support and resources, is unrealistic, and as our findings allude to, often not possible. As such, creating flexible services that employ low-barrier harm reduction strategies located *outside formal healthcare environments*, are promising steps forward to ensure all have equitable access to palliative care and the opportunity to alleviate suffering and obtain a death with dignity (Centre for Urban Health Solutions Survey Research Unit, 2017).

Ultimately, if policies and practice are to be considered in relation to structural vulnerability, supporting research is needed from both critical social sciences and a health science perspective. Engaging with critical geographical research at multiple scales simultaneously, from the broader structural (macro) to specific healthcare environments (micro), holds much promise for such an agenda. More needs to be known about how different settings impact access to end-of-life care for diverse population groups and how 'place', complexly, acts to produce, reinforce, and/or amplify inequitable access. Health geographers are well positioned for such work, particularly by contributing their expertise regarding the experiences of place in relation to emotion and affect (Bondi et al., 2012), healthcare environments (Kearns, 2018), and/or therapeutic landscapes more generally (Williams, 2010; Gesler, 1992). Further research directions will require continued collaboration across disciplinary boundaries, while employing critical and creative forms of engagement, in order to address equitable access, service/setting acceptability, and the power dynamics inherent within the places that care, at the end-of-life and beyond, is delivered.

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