



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 care¹ (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

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

¹ 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).

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