

## Original Article

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**Abstract**

**Objectives.** To analyze how structural determinants and barriers within social systems shape options for dying well at home in Canada, while also shaping preferences for dying at home.

**Methods.** To inform a descriptive thematic analysis, 24 Canadian stakeholders were interviewed about their views, experiences, and preferences about dying at home. Participants included compassionate community advocates, palliative care professionals, volunteers, bereaved family caregivers, residents of rural and remote regions, service providers working with structurally vulnerable populations, and members of francophone, immigrant, and 2SLGBTQ+ communities.

**Results.** Analysis of stakeholders' insights and experiences led to the conceptualization of several structural barriers to dying well at home: inaccessible public and community infrastructure and services, a structural gap in death literacy, social stigma and discrimination, and limited access to relational social capital.

**Significance of results.** Aging in Canada, as elsewhere across the globe, has increased demand for palliative care and support, especially in the home. Support for people wishing to die at home is a key public health issue. However, while Canadian policy documents normalize dying in place as ideal, it is uncertain whether these fit with the real possibilities for people nearing the end of life. Our analysis extends existing research on health equity in palliative and end-of-life care beyond a focus on service provision. Results of this analysis identify the need to expand policymakers' structural imaginations about what it means to die well at home in Canada.

**Introduction**

As in other countries in North America and Europe, the aging of Canada's population has meant that aging at home within age-friendly communities, and likewise, dying at home has emerged as significant policy and public health issues (Federal/Provincial/Territorial Ministers Responsible for Seniors Forum 2016; OECDiLibrary 2019). The Canadian Institute for Health Information, for instance, reports that 75% of Canadians would prefer dying at home, but that only about 15% have access to palliative home care services (Canadian Institute for Health Information 2023). A recent study of Canadians' preferred place of death showed that home was more often preferred in situations where people have secure access to help (alongside mild symptoms; Funk et al. 2022). Discrepancy between insufficient home-based palliative care service provision and majority (though not universal) preferences to die at home highlights dying at home as a fundamental equity issue. This discrepancy also prompts reflection on how we conceptualize and understand structural forces (i.e., our structural "imagination") in the context of public narratives that frame dying at home as a key component of dying well (Canadian Cancer Society 2016; Canadian Hospice Palliative Care Association 2015; Palliative Care Matters 2017). Since little is known about how equity issues intersect with preferences for dying at home in Canada, this also highlights an important research question – how might inequitable material options for dying well at home be shaped by structural forces – that simultaneously shape people's preferences for dying well at home? Such knowledge is particularly important given the tendency for inequities to be concealed in dying at home policies that embed assumptions about barrier-free access to support (Henry et al. 2017).

The focus of the present article is on supported dying in the home setting, and "dying well at home" refers to conditions promoting control, autonomy, dignity, as well as physical, psychological, social, and spiritual wellness (Kehl 2006; Meier et al. 2016; Payne et al. 1996a, 1996b; Zaman et al. 2021). Structural forces can significantly affect people's options and preferences

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in this regard (Sallnow *et al.* 2022). In this article, “structural vulnerability” refers to how inequality generates disadvantage that is reflected in dying experiences and outcomes among socially marginalized groups (Braveman *et al.* 2011; Grindrod 2020; Stajduhar and Mollison 2018; Stienstra and Chochinov 2006). We use an equity lens to analyze how structural determinants and barriers within social systems shape options for dying well at home in Canada, while also shaping preferences for dying at home (Hankivsky 2012).

### Methodology

Semi-structured interviews were conducted with Canadian stakeholders between summer 2020 and summer 2021. These interviews were a qualitative component of a larger mixed/multi-method study designed to compare expectations and meanings of dying at home among diverse subgroups; one of the early goals of the team was to consider equity implications of public policies in this regard and to include those whose perspectives may differ from the wider population. Recruitment for these interviews targeted but was not limited to the provinces of British Columbia, Manitoba, and Québec (where team members had existing ties). Using a modified key informant approach, we sought participants who could provide insights into locations of dying and preferences, either for themselves personally or for a population group with which they were familiar (e.g., through professional or personal experience). Outreach was targeted to stakeholder informants familiar with groups for which existing research indicated people might be less likely to want to die at home, including marginalized groups (Funk *et al.* 2022).

Twenty-four participants were recruited through social media and by email invitation from personal contacts of the research team. This included members of the compassionate communities movement ( $n = 4$ ), bereaved, former family carers ( $n = 7$ ), professional palliative care service providers ( $n = 8$ ), volunteers in palliative care service provision ( $n = 2$ ), service providers working with inner-city, structurally vulnerable populations ( $n = 4$ ), and members of rural ( $n = 4$ ), immigrant ( $n = 2$ ), francophone ( $n = 6$ ), and 2SLGBTQ+ communities ( $n = 3$ ) [Note: several participants spanned multiple categories, which were our main categories of interest; other sociodemographic information was not systematically recorded: see also (Funk *et al.* 2023)].

As we used a key informant approach (similar to purposive sampling) and relied on some of our own networks (similar to convenience sampling), the sampling process was not designed to represent a broader population (Marshall 1996). As such, non-response rates were not recorded. To determine the stop point for recruitment, we carefully weighed whether we had “enough” high-quality data overall to contribute to a comprehensive conceptual analysis (Morse 2000). Prior to starting recruitment, this research was approved by the University of Manitoba’s Research Ethics Board, Fort Garry (P2019:091), the University of Victoria Human Research Ethics Board (19–0096), and the Medical/Biomedical Research Ethics Committee of the CIUSSS West-Central Montreal Research Ethics Board (2020–1963).

Semi-structured qualitative interviews (roughly 1 to 2 hours in duration) were audio-recorded over ZOOM due to COVID-19 restrictions and geographic distance. Participants were offered honoraria at the time of the informed consent procedure, regardless of interview completion. One-to-one interviews at one time point were conducted by Cherba, Funk, and graduate-level research assistants trained by Funk. Field notes were not

recorded, and participants did not review transcripts. Two interviews completed in French language were translated for analysis. Participants were asked to describe and explain their personal preferences for location of death if dying of expected illness, as well as what it meant to them to die at home and why. For those with professional, volunteer, or advocacy-related experience or expertise related to a specific population group, they were asked to comment on the same for members of this group. In the latter comments, participants frequently referred to material forces shaping peoples’ abilities to die well at home.

### Data analysis

Preliminary analyses and later verification of the findings involved the interdisciplinary, international, mixed-gender research team that designed the study, including PhD trained academic researchers from nursing, psychology, anthropology, gerontology, and sociology. Chan and Funk, a health sociologist and social gerontologist, respectively, collaborated closely on a descriptive thematic analysis of interview content informed by an equity lens, which combined inductive and deductive elements to formulate the constructed conceptual themes representing structural barriers shaping both dying well at home and, to lesser extent, preferences for dying at home. General steps included data familiarization (repeated rereading and immersion and conversations with interviewers), generating initial coding (i.e., 18 codes about personal preferences of dying at home; 40 codes about barriers; 5 codes about solutions), developing and reviewing thematic categories/themes (25 categories about barriers), and redefining and naming conceptual themes (4 conceptual themes). The coding and conceptualization process drew on a constant comparative method (a method commonly “borrowed” from grounded theory) to facilitate development of the final conceptual themes (Glaser and Strauss 1967). The analysis evolved iteratively through manuscript writing and revision by the broader team, many of whom were highly familiar with the data. To support trustworthiness, an audit trail within NVivo qualitative analysis software recorded the process of code naming, defining, and theme generation (Nowell *et al.* 2017). Chan and Funk drafted and shared memos and tables to illustrate and discuss coding rationales and paradigms throughout the process (Nowell *et al.* 2017). Participants were sent summaries of our preliminary analysis with the option to comment.

### Results

Across the interviews with stakeholders who spoke about dying at home preferences and experiences, our analysis conceptualized four structural barriers to dying well at home in Canada, which also illuminated how these forces can inform peoples’ preferences for dying at home.

#### **Theme 1: Inaccessible public and community infrastructure and services**

Participants identified inaccessible public and community infrastructure and services as a primary structural barrier to the ability to die well at home, which exacerbated geographic and socioeconomic inequities. Such barriers also appeared to temper peoples’ expressed preferences for dying at home.

Participants frequently commented on the unavailability of home-based palliative care services, especially in rural and remote

regions, and emphasized how financially advantaged people can pay privately for additional services. Notably, relevant infrastructure and service considerations extended beyond traditional palliative home-based supports. For instance, affordable housing with appropriate space can be an essential environmental determinant of dying well at home. A palliative care service provider from the province of Québec noted:

The physical [interior] of the house is a huge barrier. If somebody is in an old house and the only bathrooms are upstairs, then the person is like a prisoner because they cannot come down to the main floor to cook meals or anything. (Case 21)

For structurally vulnerable populations, unsuitable housing often precluded the possibility of dying at home (Stajduhar and Mollison 2018). Housing precarity generates vulnerabilities for street-involved drug users, where the meaning of death and dying is often intertwined with preexisting trauma. In the words of one advocate:

I think the experiences [of dying] are really poor and full of trauma and unresolved grief and loss. So it is like almost, the notion of a good death is so far away from the reality of so many people. Like, the overdose and the overdose crisis obliterate the community. (Frontline practitioner for structurally vulnerable populations, Case 7)

Some participants, such as the individual quoted below who was involved in a compassionate communities initiative in British Columbia, discussed how specific housing models and resources can enhance mutual support for those dying at home.

Housing and neighborhood planning can be important for people to age and die at home ... create new co-op housing, self-governing intergenerational community-oriented housing, with community mutuality built into the model, which supports people to age in place and die at home with support. (Case 4)

Unsuitable or inaccessible housing as well as lack of access to publicly funded services negatively impacts peoples' capacity to choose where they wish to die, which may lead to a kind of "resigned acceptance".

### **Theme 2: A structural gap in death literacy**

The concept of death literacy as currently developed entails multiple components but generally focuses on individual and community-level knowledge and skills acquired through experiential learning (Noonan et al. 2016; Nutbeam 2000). Participants in the present study emphasized how the lack of societal exposure to and education about death and dying created a gap in knowledge and skills about dying at home and its support. A palliative care professional and volunteer in Québec explained that when families lack strong skill sets for caring for dying persons, they are more likely to call an ambulance and have the dying person admitted to hospital (Case 11). A nurse clinician (Case 23) in a community-based nonprofit palliative home care program also emphasized how needed knowledge can shift as an illness progresses, underscoring the importance of honest and ongoing conversations between families and health-care providers who are themselves comfortable talking about this topic.

Low death literacy is further exacerbated by poor information from governments and fragmented public systems that create system navigation challenges. A service provider for aging members

of the 2SLGBTQ+ community emphasized equity considerations in this regard:

I would want the government to make sure there were adequate resources, professional resources, professional support, not just from a medical perspective, but also social ... supportive ... practical information, and written in easy language, written in different formats... (Case 13)

Similarly, new immigrants trying to learn about and access supports for dying at home may face additional navigation challenges in communities with low death literacy, especially where relevant information is not available in multiple languages.

Death literacy does not mean people should embrace an idealized vision of dying at home. Instead, most participants in this study echoed the need for nuanced and critical public awareness of when dying at home may not be appropriate or ideal under particular circumstances and when dying well at home may be less feasible. In part, this was a recognition of structural barriers and inequities; however, participants also spoke about this in ways that highlighted the needs for adequate communication with the public about the realities involved in dying well at home and the need for advance preparation. For instance, one participant referred to some survey data that had been released in their region:

There is clearly more than 50% of people who said they wanted to die at home [in that survey], but at the same time, people don't have wills, and people don't make the prerequisite arrangements. Have they really thought about it or do they just say, yeah, everyone wants to die at home, why go to the hospital. (Palliative care professional from Québec, Case 23)

### **Theme 3: Social stigma and discrimination**

Stigma and discrimination manifesting within supportive institutions and services, such as outpatient palliative care, formal home care, or emergency hospitalization, reflect power relations and life course exclusion and can exacerbate the vulnerability of marginalized groups in ways that extend into the end of life. Stigma and discrimination can also unduly influence whether, how, and when people wishing to remain at home access palliative services and supports. A volunteer working with marginalized and rural communities on Canada's East Coast explained how, for precariously housed persons with mental illness or addictions, discrimination related to their mental illness or addiction restricts access to service, even when there are palliative diagnoses.

[...] barriers about access to services and having to be sober, for one. People could be presenting as intoxicated and that could be that they're a diabetic. So, there's having this medical understanding or empathy.... (Case 19)

Moreover, when there is stable supportive housing for these individuals, discrimination embeds within housing policy to restrict dying persons' access to service, as whole buildings become deemed "unsafe" for care providers to enter. In this way, supportive services can conflict with and thereby unintentionally reduce capacity to die well at home.

Other forms of discrimination can increase people's expressed preferences to die at home in ways that problematize the idea of choice. A transgender participant from the East Coast highlighted the exclusion of sexual and gender nonconforming persons in hospital as a driver of their own strong preferences for dying

at home, a situation in which such preferences are distinctly less voluntary:

[...] being in a hospital room [sigh] Noooo, thank you. Being in, palliative care wards? I've talked to other people in my 2SLGBTQ+ community, and [pause] right now, in this country, I don't think I'm going to be welcomed, in any of these end-of-life facilities. I'm going to be tolerated ... so that really isn't an option. (Case 12)

Meanings of dying at home, including views of a “good death,” vary by culture, religion, and ethnic identity. Participants emphasized how discrimination can manifest in service, practice, and in policy insensitivity to cultural and religious rituals in and after dying at home. A South Asian immigrant of Hindu background (Case 20) from Ontario, for instance, expressed a preference to die at home near to loved ones, yet was hesitant not knowing about whether her body and remains could be dealt with appropriately, according to the religious rituals of her caste, in Canada. Another participant (an advocate for immigrants, Case 10) spoke of how terminally ill persons may wish to return to their country of origin if that is the only place where they can be confident of the proper enactment of religious rites and rituals. Canadian policy and practice tend to limit attention to care after death, which for many cultures is problematic can impact preferences.

#### **Theme 4: Limited access to relational social capital**

Trusting, often informal, social connections, and networks in families and communities are fundamental to supporting positive experiences of dying at home. Alongside the engagement of more formalized community volunteer organizations, informal connections generate relational and tangible resources for mutual aid and reciprocal care that can be conceptualized as social capital (Horsfall et al. 2012). Participants emphasized the importance of having access to supportive networks, given how dying at home is dependent on support from family and friends. For instance, a member of a nonprofit organization that supports aging members of the 2SLGBTQ+ community (Case 12) emphasized how queer persons often have less access to traditional family-based supports. To die well at home, they must rely on “families of choice.” Another participant from Manitoba (Case 10) expressed concerns about how COVID-19 had eroded social connections in her neighborhood, leaving one of their recently bereaved neighbors unsupported. She also explained how newer immigrants face particular disadvantage in terms of access to family and smaller long-term social networks, and thus how some new immigrants diagnosed with a terminal condition wish to return to their country of origin to access richer social networks and community connections (if they can afford financially to do so). As such, access to deeply connected relational support informs people's preferences for death “at home” as well as access to hands-on care needed to die well at home.

Broader structural forces including divorce trends and declining fertility shape access to family resources and have implications for family care capacities even among those who are not facing structural vulnerability. For example, one palliative care social worker explained with regards to her situation: “my parents are divorced, so it's not just two couples that my spouse and I have to care for, but four people” (Case 24). Well-resourced families may be able to mitigate some of these pressures by paying privately for nursing and home care services. Adding further complexity to this theme, however, is that peoples' reluctance to burden the

family with end-of-life care may also result in preferences to *not* die at home.

## **Discussion**

This study uses an equity lens to examine and conceptualize the impact of structural barriers to dying well at home in Canada, while considering how such barriers simultaneously shape people's preferences in complex ways (Dhamoon and Hankivsky 2011; Hankivsky 2012). Four constructed themes were generated in the analysis related to inaccessible public and community infrastructure and services, a structural death literacy gap, social stigma and discrimination, and limited access to relational social capital.

This analysis adds to and extends existing research in several ways. First, our findings highlight the political and economic forces shaping inequities in dying experiences, for instance through shaping access to funded care and support across the life course. As well as intersecting with other forms of social exclusion, socioeconomic status shapes access to formal resources at the end of life, including housing and care, as well as the availability of family members who can provide care (Chen et al. 2015; Wales et al. 2018). Families experiencing financial hardship and those in rural areas are less able to privately compensate for disparities within and between provinces in palliative end-of-life care and home care support (Bowers et al. 2022; Conlon et al. 2019; Morduch and Siwicki 2017; Seow et al. 2018; Williams et al. 2010). Moreover, financial hardship can also be induced through the process of supporting a family member to die at home. As such, lower-income Canadians are more likely to die in acute care or palliative care units than at home (Government of Canada 2023; Wales et al. 2020).

Second, participants indicated death literacy as shaping preferences for and capacities to die at home. A lack of death literacy can generate uncertainty about caring for persons dying at home (Ladin et al. 2018) or be a barrier to emergency care planning (Witham 2022). Death literacy should include critical recognition of practical constraints that counter the idealization of home death, as well as equity-related implications. The information about dying at home and end-of-life care is limited in languages other than English (Yarnell et al. 2020).

Third, our study adds to other research, which has highlighted limited options available to dying persons from diverse cultural, religious, and ethnic backgrounds, as well as social stigma and discrimination (Giesbrecht et al. 2018). Collectively, this research highlights the power relations shaping dying experiences (Quach et al. 2021; Yarnell et al. 2020). Institutional supports for palliative care can exacerbate inequities in dying well at home among marginalized groups while shaping their dying at home preferences in complex ways. Our study highlights issues in this regard such as culturally insensitive and discriminatory practice, service, and policy (Dhamoon and Hankivsky 2011; Giesbrecht et al. 2018; Kortés-Miller et al. 2018).

Fourth, in Canadian palliative care policy, there is a standardized expectation that people dying at home have a developed family and friend support network and access to community-based support (Henry et al. 2017). Whether such expectations align with the context of changing family structures, employment patterns, and increasing immigration in this country (which may reduce people's relational social capital) needs to be more fully reflected and considered in policy and program development and delivery.

Fifth, while compassionate community initiatives contain some promise for developing informal support networks in communities to address death and dying (Sallnow et al. 2022), it is possible they

cannot be relied upon to address more structural problems and inequities. Community development approaches might, however, if themselves adequately funded, engage a wide variety of stakeholders and help enhance broader public support and acceptance for dying persons and their families (Abel and Kellehear 2022), with potential for diversifying community participation and building different types of social capital to help support dying well at home (Rosenberg et al. 2015; Sawyer et al. 2019; Walshe et al. 2016), advocating to address social and institutional exclusion (Librada-Flores et al. 2020), and building community death literacy (Noonan et al. 2016). By passing the Bill C-277 in 2017, the Canadian government has a responsibility for driving the improvement of palliative care with local, provincial, and federal stakeholders in Canada (House of Commons 2017). Both the possibilities and limitations of compassionate communities in shifting more structurally rooted barriers to dying well at home remains need to be more fully explored.

Lastly, our findings start to illustrate a complex intersection between barriers shaping options for dying well at home and expressed preferences. Future research could more specifically target and examine these issues using an intersectionality framework (Crenshaw 2017). This framework questions the meaning of and relationship between different social categories, going beyond the assumption of static and essentialized linkages between determinants and outcomes toward understanding the complex interplay of different social forces shaping diverse experiences (Hankivsky and Christoffersen 2008; Hankivsky et al. 2014). Such an approach can further examine issues of equity concerning dying at home in Canada (Hankivsky 2012; Hankivsky and Christoffersen 2008), contributing to making dying in place a more equitable option.

### Strengths and limitations

This analysis has helped illuminate stakeholders' experiences and perspectives of barriers shaping dying well at home, as well as preferences for dying at home. Our interpretation highlights points of intersectionality, with implications for equity related to various social positions and conditions. Alongside other research, findings can inspire policymakers' "structural imagination" to grasp the significance of wider service and policy visions beyond "palliative care" per se, such as suitable housing, social capital development within communities, and death literacy and education. These insights could inform the international discussion of policy and service supporting dying well at home and end-of-life care in communities (Sallnow et al. 2022).

However, this study has several limitations. Our findings may not comprehensively address situations in all regions, provinces, and social groups in Canada and beyond. Further studies are needed to enrich our understanding of the complex issues of dying well at home. For example, there is a need to unpack the assumptions regarding dying at home – is dying in place more appropriate as not everyone has a home. Also, how to explore further the policy discussion of dying at home but death in hospital which is part of the continuum of care for the dying. In addition, the ability of these data to illuminate the intersectionality of different social and structural determinants shaping inequities in dying at home experiences was also limited. Further studies designed using an intersectionality perspective may help health-care service and policy address such inequities (Holman et al. 2021). Lastly, physical distancing during the pandemic constrained the interaction between researchers and informants in the data collection process

(which was conducted over ZOOM), which may have affected the depth and richness of information we collected.

### Conclusion

Canada faces the complex challenge of supporting dying individuals to die at home. Our study indicates that the structural barriers of inaccessible public and community infrastructure and services, a structural gap in death literacy, social stigma, and discrimination, and limited access to relational social capital deserve further scrutiny with an intersectional lens. Addressing these barriers and advancing comprehensive solutions will contribute to a more compassionate and inclusive society, helping to ensure that the needs of dying individuals in Canada are met.

**Supplementary material.** The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951523001074>.

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**Competing interests.** The authors declares that there is no conflict of interest.

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