

# Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end-of-life

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## Abstract

**Background:** People experiencing structural vulnerability (e.g. homelessness, poverty, racism, criminalization of illicit drug use and mental health stigma) face significant barriers to accessing care at the end-of-life. ‘Family’ caregivers have the potential to play critical roles in providing care to these populations, yet little is known regarding ‘who’ caregivers are in this context and what their experiences may be.

**Aim:** To describe family caregiving in the context of structural vulnerability, to understand who these caregivers are, and the unique challenges, burdens and barriers they face.

**Design:** Critical ethnography.

**Setting/participants:** Twenty-five family caregivers participated. Observational fieldnotes and semi-structured interviews were conducted in home, shelter, transitional housing, clinic, hospital, palliative care unit, community-based service centre and outdoor settings.

**Results:** Family caregivers were found to be living within the constraints of structural vulnerability themselves, with almost half being street family or friends. The type of care provided varied greatly and included tasks associated with meeting the needs of basic survival (e.g. finding food and shelter). Thematic analysis revealed three core themes regarding experiences: Caregiving in the context of (1) poverty and substance use; (2) housing instability and (3) challenging relationships.

**Conclusion:** Findings offer novel insight into the experiences of family caregiving in the context of structural vulnerability. Engaging with family caregivers emerged as a missing and necessary palliative care practice, confirming the need to re-evaluate palliative care models and acknowledge issues of trust to create culturally relevant approaches for successful interventions. More research examining how ‘family’ is defined in this context is needed.

## Keywords

Family caregivers, vulnerable populations, poverty, ethnography, Canada

### What is already known about the topic?

- At the end-of-life, people experiencing structural vulnerability face inequitable barriers in accessing care.
- Issues of safety and trust impact structurally vulnerable populations’ healthcare experiences and interactions.
- Family caregivers may play pivotal roles in providing end-of-life care for structurally vulnerable populations, however, ‘who’ family caregivers are, and their experiences in this context, are largely unknown.

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**What this paper adds?**

- Family caregivers for people experiencing structural vulnerabilities were often street family or friends and found to be experiencing structural vulnerability themselves.
- Poverty and unstable housing contributed significant stress for family caregivers, with stigma, addictions and substance use creating major barriers to accessing support.
- Complex relational tensions resulted in caregivers having to delicately navigate issues of power, trust and control, especially over decision-making, within the caregiver/recipient relationship.

**Implications for policy, practice and research**

- Family caregivers, particularly those caring for structurally vulnerable people, must be included and engaged with when determining best practice in palliative care.
- Revising existing palliative care models to acknowledge diversity of lived experience, issues of trust and to create culturally relevant approaches for successful interventions and support is necessary.
- More research examining how 'family' is defined in the context of structural vulnerability is needed.

**Background**

Inequities experienced by structurally vulnerable populations become particularly pronounced at the end-of-life.<sup>1–12</sup> The concept of structural vulnerability is aligned with a social determinants of health perspective, but builds upon it to capture the wider range of social and structural forces that produce and reinforce inequities, constrain agency and opportunities, and amplify vulnerability to risk, harm and poor health.<sup>13,14</sup> Structural vulnerability, therefore, is the product of one's location within the social hierarchy, where relationships of power are embedded,<sup>15</sup> and encompasses not only political and economic inequalities, but also a wider range of cultural determinants (e.g. the medicalization/pathologization of 'at-risk' populations, cultural views on the 'worthiness' of particular groups, etc.). This study focuses on populations experiencing structural vulnerability as a result of living in poverty and experiencing various levels of homelessness. These experiences are simultaneously and differentially shaped by racism, settler colonialism, experiences of trauma and violence, social isolation, stigma associated with mental health issues or cognitive impairments, substance use, experiences of incarceration and disability.<sup>3,5,6</sup>

At the end-of-life, people experiencing structural vulnerability face significant barriers in accessing care.<sup>4,11</sup> Findings from our previous work indicates that barriers to care for these populations include the need to prioritize daily survival, the normalization of death and dying in their lives, problems associated with recognizing the need for palliative care, policies regarding professional risk and safety management, and disjointed health and social care systems.<sup>5</sup> In addition, Ko et al.<sup>10</sup> found that homeless adults avoid seeking medical care at end-of-life out of fear of discrimination and being viewed as unworthy of treatment. Other previous research of ours indicates that those with life-limiting illnesses who are experiencing structural vulnerability simply do not 'fit' into public, formal healthcare environments, yet

have *no place else to go* to access needed care.<sup>6</sup> In response, there have been recent calls to action for palliative care to become more flexible and mobile.<sup>4,7,16–18</sup> This includes bringing palliative care into settings deemed acceptable and safe by structurally vulnerable populations in order to meet clients 'where they are at'.<sup>7,16</sup> Palliative care in informal settings, however, requires a multi-disciplinary team of providers, including informal/family caregivers who ultimately provide the bulk of physical, psycho-social and emotional end-of-life care in these community/home settings.<sup>19</sup> Furthermore, considering that feelings of safety and trust play significantly in the role of structurally vulnerable populations' seeking out and accessing care,<sup>6,8,9</sup> family caregivers, who have pre-existing, trusting relationships have the potential to play critical roles in ensuring palliative care is being received. However, 'who' family caregivers are in this context and their experiences fulfilling this role is largely unknown.

**Aim**

This analysis builds upon a larger critical ethnographic study that examined access to care for structurally vulnerable people at end-of-life.<sup>5</sup> Our current focus is to describe family caregiving in the context of providing palliative care to people experiencing structural vulnerability. More specifically, we seek to understand who these caregivers are and what challenges, burdens and barriers they face. Our purpose is to promote the inclusion of these family caregivers, and their experiential knowledge, to generate findings that may inform the development of more equitable programmes and policies.

**Methods****Design**

Critical ethnography aims to qualitatively explore the nature of specific social phenomena in the environments

that they occur,<sup>20</sup> while generating knowledge for change.<sup>21</sup> Thus, this methodology is well suited for conducting research with structurally vulnerable populations and in addressing our aims.

### Setting

The study took place in an urban area in British Columbia, Canada from September 2014 to March 2017.

### Sampling and recruitment

The sample for the larger study was comprised of three participant groups: (1) people experiencing structurally vulnerability who were on a palliative trajectory; (2) their support persons and (3) their formal service providers (e.g. housing workers and medical professionals). Recruitment involved inviting local health, housing and social care service providers to participate via pamphlets, posters and presentations circulated in places of employment. Consenting health care providers who worked in community-based inner-city settings then facilitated recruitment of participants experiencing structural vulnerability by identifying those on a palliative trajectory (i.e. those with a life-limiting medical condition) and sharing letters of invitation with them. Some consenting structurally vulnerable participants had informal support persons (e.g. biological family members, 'street' family and chosen supporters), who were also invited to participate.

### Data collection

Repeated participant observations with structurally vulnerable participants ( $n = 25$ ) and their family caregivers ( $n = 25$ ) occurred over 30 months, resulting in approximately 300 h of fieldwork. Researchers and research assistants did not have pre-existing relationships with participants, however, all had previously worked with structurally vulnerable populations. For instance, research assistants had backgrounds working in harm reduction, street outreach, and street nursing, and had extensive training in cultural safety, and trauma and violence-informed care. Observations were conducted during day and evening hours in homes, shelters, transitional housing units, clinics, hospitals, palliative care units, community-based service centres and outdoors (e.g. street and parks). Observational data were supplemented with family caregiver in-depth interviews ( $n = 16$ ) to enhance clarity and confirmation on what was observed. Interviews were conducted by the same researcher who conducted observations with that particular participant to enhance longitudinal continuity of data collection and because building trust with participants was crucial. Interviews occurred in settings selected by participants (e.g. homes, coffee

shops, parks, etc.). All interviews were digitally recorded, transcribed verbatim and together with observational fieldnotes, entered into NVivo™ for analysis.

### Data analysis

This analysis draws on data collected with 25 support persons. We used the phrase 'support persons' in the primary study to denote those who provided physical, psycho-social, and emotional care, and practical support, akin to descriptions of 'family caregivers' in the literature. Data collection and analysis occurred concurrently.<sup>22</sup> Data were organized thematically using an iterative and inductive process,<sup>23</sup> including open coding to develop broad categories that were then refined and recoded.<sup>22</sup> This analysis draws on data initially coded as 'experiences providing care', which was then refined to capture and unveil the experiences of the support person/family caregiver participant group. Throughout the analytic process, numerous team meetings were held to review data and emerging themes and develop coding schemes, which enhances analytic rigour.

### Ethical considerations

Ethics approval was obtained by UVIC/VIHA Joint Research Ethics Sub-Committee (Number: J2014-028) on July 23, 2014. Written consent was obtained by all participants, with ongoing verbal consent continually confirmed during the data collection process. To ensure anonymity, participant pseudonyms have been used.

### Findings

#### *Characterizing family caregivers of structurally vulnerable populations at end-of-life*

Findings indicate that many family caregivers were themselves experiencing structural vulnerabilities (e.g. poverty, homelessness, racialization, discrimination, stigmatization, criminalization and social exclusion). Furthermore, some family caregivers were also on a palliative trajectory, resulting in a complex caregiver/care-recipient relationship, whereby each could be characterized as both a caregiver and care-recipient. These structurally vulnerable caregivers faced significant inequities in accessing supports, which exacerbated their vulnerability. Demographic characteristics are presented in Table 1.

The types of care provided was found to vary greatly, ranging from intense and ongoing care (e.g. personal care, medical care, care coordination, pain and symptom management, psychosocial care) to more pragmatic support such as obtaining food and medications, to contacting estranged family members prior to death and making funeral arrangements.

**Table 1.** Informal caregiver participant characteristics (*n* = 25).

Participant characteristic	Number of participants
<b>Relation to care recipient</b>	
Friend and/or street family	10
Biological family	10
Former or current partner	5
<b>Gender</b>	
Men	11
Women	14
<b>Age range (years)</b>	
35–44	8
45–54	4
55–64	3
65–74	3
<b>Race/ethnicity</b>	
White/European settler	12
Indigenous	6
Did not respond	7
<b>Marital status</b>	
Divorced/separated	3
Single	9
Married/common-law	6
Did not respond	7
<b>Sexual orientation</b>	
Heterosexual	16
LGBTQ	2
Did not respond	7
<b>Educational attainment</b>	
Some high school	5
Completed high school	2
Some college/post secondary	7
Completed college/post secondary	4
Did not respond	8
<b>Housing status</b>	
Homeless (e.g. shelter, boat and hospital)	3
Social or public housing	2
Market housing	11
Home owner	2
Did not respond	7
<b>Main source of income</b>	
Provincial disability benefit	3
Social assistance	4
Pension	4
Employment income	6
Other	1
Did not respond	7
<b>Health status</b>	
Life-limiting conditions	
Arthritis	5
Cardiovascular disease	3
Chronic obstructive lung disease	3
Cancer	1
Diabetes	1

*(Continued)***Table 1.** (Continued)

Participant characteristic	Number of participants
<b>Other conditions</b>	
Hepatitis C	4
HIV/AIDS	1
Self-reported mental illness	5

Participant data does not equal 25 in the following categories because data are missing: age groups, race/ethnicity, marital status, sexual orientation, educational attainment, housing status, and source of income. LGBTQ: lesbian, gay, bisexual, transgender and queer.

### *Thematic analysis*

Thematic analysis resulted in identification of three core themes: caregiving in the context of (1) poverty and substance use; (2) housing instability and (3) challenging relationships.

### *Caregiving in the context of poverty and substance use*

Caring for those who are structurally vulnerable shapes experiences of caregiving. For some, their lives were centred on meeting daily survival needs, including finding/buying food. ‘Roger’, who when asked what they do when their finances are limited, replied that they simply ‘go hungry’. Other participants had access to minimal income through lower wage, and often precariously paid employment, that did not provide workforce benefits like ‘paid leave’. While caregivers were working, care recipients were left on their own, sometimes for long periods of time, and often had to attend healthcare appointments alone. This resulted in great caregiver stress as they worried over the safety of care recipients being/travelling on their own (often via public transport), and which also meant they were absent from important healthcare interactions. As ‘Lenora’ explains, this can be incredibly problematic, particularly if the care recipient has health literacy issues: ‘That was the biggest challenge, when she got diagnosed with her terminal cancer, she went to the appointment alone and she didn’t understand what the doctor told her’. A month went by before ‘Lenora’ learned what was shared at that appointment and why ‘Betty’ had continued to say that her doctor appointments had been cancelled. The doctor had told her, there was ‘nothing more he could do’.

Substance use significantly shaped experiences of caregiving. The stresses of caregiving without formal support and/or training triggered some participants to use substances as a coping mechanism. ‘Wayne’ shared: ‘I think he [care recipient] was using more. I kind of used more as well I think. It was hard seeing a friend going

through pain and then, ultimately, dying day by day'. Not all caregiver participants used substances, but some reported that health professionals assumed they did and explained their challenges in getting proper help for pain management. 'Roger' explained: 'Obviously, it is about people that are addicts, and being so, you get stigmatized and are not given proper medication, or proper amounts to deal with pain management'. Participants expressed frustration over stigmatizing attitudes about addiction and diversion, noting that this placed limits on their ability to administer needed medications (e.g. opioids for pain and benzodiazepines for breathlessness). Therefore, within the context of stigma and addictions, caregivers' capacity to fulfil their role was significantly hampered, restricting opportunities to caregive or facilitate an individual's request to be cared for and die 'at home'. Restrictive risk and safety policies that prevented formal home care providers' ability to enter into homes that were deemed unsafe (e.g. presence of drug paraphernalia and cigarette smoke) also hampered caregiving. Thus, poverty and substance use dramatically shaped family caregivers' experiences and their capacity to provide care in environments that care recipients may feel most comfortable, secure and safe.

### *Caregiving in the context of housing instability*

Limited access to safe, secure and stable housing made caregiving a challenge. While all care recipients experienced housing instability, so too did family caregivers. This meant that health services, such as home care, could not be deployed and caregivers were left to provide care on their own in precarious environments. Declining physical health, and greater care needs, actually increased care recipients risk of being evicted and losing their housing. After eviction, 'Jimmy' shared how the hospital was suggested as the only place they could go:

She [care recipient] had a huge ulcer on her foot, she was ordered to stay in bed throughout this whole thing while we were looking for places [because she was being evicted]. She has case managers, and she would ask, 'Where am I supposed to go?' and the case manager told her, 'Well, just go to the hospital'.

Left with little choice, 'Jimmy' 'wheeled' his dying friend to his own apartment, even though it went against building policies and, ultimately, put his own housing at risk. Many caregivers shared that they felt obligated to conceal the declining condition of their dying friends in an effort to allow them to remain 'at home'. Out of fear of losing their housing, needed services and supports that would ensure quality end-of-life care were simply not sought by caregivers.

Many caregivers, some of whom were also very sick, wished to cohabit with care recipients to provide ongoing care. Yet housing policies (e.g. single occupancy) prevented them from living with care recipients. This created high levels of stress and placed an even greater burden on caregivers, who were left with little choice but to travel daily, sometimes far with limited financial resources, to provide needed care. For example, 'Wayne' travelled up to 2 h daily to provide care for his dying friend. Other housing policies (e.g. no guests allowed and no medical equipment allowed) were so restrictive for caregivers' that care recipients were forced to move, often into precarious housing and sometimes even the street. The systemic barriers resulting from housing vulnerability created highly distressing situations for caregivers and care recipients, who in the context of dying found themselves with no place to provide/receive palliative care.

### *Caregiving in the context of challenging relationships*

Caregivers of people who are dying and experiencing structural vulnerabilities have to navigate complex relationships in a context where the person they are caring for may distrust others, have minimal contact with biological family, and may be perceived by others as incapable of making 'good' or 'healthy' decisions. Participants reported experiencing a lifetime of having their needs neglected or having others try to 'change' or 'control' them. Many caregivers expressed having to 'tread lightly' or give recipients 'a very long leash' to maintain trusting relationships. For example, 'Rob' described how he was 'trying to facilitate him [care recipient] moving into a fairly stable structure [housing facility], but his perception of things would be "no, you're trying to control me"'. 'Rob' went on to say how he had to 'back off. . . but it was really tough to kind of [say] okay, yes, we know what's best, but unfortunately it's his choice'. Some caregivers did, however, put their relationships at risk by making critical decisions on behalf of care recipients. 'Alex' shared his distress when deciding to go against his friend's wishes to do what he felt was needed; he explained his friend wanted to die on his boat that was anchored in the ocean. After watching him struggle in pain and deeming the situation unsafe, 'Alex' decided to have his friend removed from the boat. This decision jeopardized their friendship when his friend was admitted to hospice care. Although the caregiving relationship ended, 'Alex' believed this decision to be the most humane:

Someone had to make a decision and everyone's dream has to come to an end, you know? He would have stayed there [on the boat] until he died. It was probably his final wish, to die on the water. But when I seen the pain that he was in, I thought, you know, to leave him be, would be inhumane.

Other participants described the stresses involved when caring for recipients who lived unpredictable lives. Many shared instances of not knowing where care recipients were, for example if they were incarcerated, had left the province, were in the hospital, or just avoiding contact. 'Rob' described how he 'would be up at all hours trying to find' his brother whom he was caring for.

Relational tensions often arose between street family members and estranged biological family members, who in some cases only made contact with care recipients just prior to death. This was difficult for caregivers who had long-standing familial-like relationships with care-recipients, but were not recognized by the legal/healthcare system or biological family as being 'family'. For example, despite 'Loretta's' 12-year intimate relationship with her partner, it was the estranged biological family who held power over what happened with his body after death. 'Loretta' explained how he had 'died in [her] arms' and now the biological family were 'trying to take his body away'. Although 'Loretta' and her friend considered themselves common-law partners, they were not legally recognized as such because they did not meet the Canadian definition, which requires 'living together' for 2 or more years. Observational fieldnotes explain that: 'they have lived together off and on in housing facilities, but due to the restrictions of these housing facilities, they have not "officially" lived together'. As a result, 'Loretta' experienced significant systemic barriers due to her structural vulnerability (e.g. housing status and poverty), which created inequitable caregiver burden and distress. 'Loretta', with minimal access to material resources (e.g. telephone, computer and transportation) and social/legal power, was forced to fight the biological family and the health and legal system to find out where her partners' ashes were and who would obtain them.

## Discussion

### *Main findings*

Our findings provide novel insight into the lived experiences of family caregivers, and the valuable role they play, at the end-of-life in the context of structural vulnerability. These family caregivers were found to often live under the constraints of structural vulnerability themselves, with almost half being street family or friends. The care provided varied greatly (e.g. personal, psychosocial, care coordination and post-death care) and often involved assisting people in meeting the needs of basic survival. Poverty and unstable housing was an overarching factor shaping caregiving experiences, contributing significant stress to the already high demands of caregiving at end-of-life. Caregivers faced barriers related to stigma, addictions and substance use. Housing instability meant there was often no safe and secure environment to provide care or have formal home care come in to assist and support them in their role. Complex relational tensions were also

found to exist. Caregivers commonly shared how they were forced to delicately navigate issues of power, trust and control, particularly over decision-making within the caregiver/recipient relationship. Street family and friends, despite their close relationship with care recipients, shared how they were often left out of conversations and critical decisions because they were not deemed 'family' by the legal and healthcare system.

### *Implications for policy and practice*

Unpaid family caregiving has become one of the most important social and economic policy issues worldwide.<sup>24</sup> Family caregiving does bring positive experiences,<sup>25</sup> but it can also take a significant toll physically, emotionally, psychologically and financially.<sup>26–28</sup> At the end-of-life, care intensifies, resulting in increased risk of caregiver stress, anxiety, depression, social isolation, as well as morbidity and mortality.<sup>26,29,30</sup> It is important to recognize, however, that caregiver experiences are highly diverse, shaped by one's lived context, social positioning, access to resources and supports and capacity for resilience.<sup>30–35</sup> However, little research acknowledges such diversity or considers who needs what kinds of supports. Considering their valuable role and contributions, it is crucial to recognize family caregivers, understand their needs, and how to enhance their access to meaningful supports.<sup>19,36</sup>

While more research is needed, our findings suggest that the relatively minimal, one-size-fits-all caregiver supports that currently exist in Canada (e.g. palliative home care and employment insurance programmes)<sup>37</sup> hold little relevance for structurally vulnerable populations. Many participants did not have safe or secure housing, rendering home care support inaccessible,<sup>5,6</sup> and employment status often deemed participants ineligible for financial assistance.<sup>31</sup> Therefore, participants endured the weight of caregiving on their own, doing what they could from within the harsh constraints and limitations imposed on them. Not only did participants face the commonly described family caregiver burdens that are experienced by the general, normative, population,<sup>27,28,38</sup> but they also bore the responsibility of finding basic requirements for daily survival, while experiencing stigmatization and judgement. Many were already living in poor health, with some on palliative trajectories themselves. Barriers in accessing supports resulted in participants attempting to fill the cracks of a disjointed social and health care support system. Failing to support these caregivers only serves to amplify pre-existing vulnerabilities, create significant distress, and ultimately increase their need for health and social services.

### *Limitations*

This study was not focused on experiences of family caregivers, so their perspectives were not primarily sought throughout the data collection process. However, their

presence during observations allowed us the opportunity to gain a glimpse into their everyday experiences. Interviews with these participants also allowed the opportunity for them to share a deeper contextualization of their experiences. While caregiving experiences will vary greatly, many of the challenges faced by participants are transferrable to outside a Western Canadian urban centre, across geographies at various scales, rural/urban and international.

## Conclusion

Emerging research has begun to suggest strategies for enhancing access to palliative care for structurally vulnerable populations by meeting them 'where they are at', not only geographically in shelters, on the streets, and in housing units that may be traditionally deemed 'unsafe' by the formal health care sector, but also socially, to ensure they feel safe and are surrounded by care providers capable of providing them with comfort.<sup>4,6,16,39–41</sup> Considering this, family caregivers have the potential to play a pivotal role, yet they must first be recognized as valuable members of the care team. Engaging with family caregivers of the structurally vulnerable emerged as a missing and necessary palliative care practice, confirming the need to re-evaluate palliative care models and acknowledge issues of trust to create culturally relevant approaches for successful interventions. What is meant by 'family' in the context of structural vulnerability needs to be further examined to describe more fully who these caregivers are. Further research is also needed to better understand the varying complexities of how this population is cared for at the end-of-life and what tools may be utilized to better support family caregivers of structurally vulnerable populations.

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## Author contributions

K.I.S. developed the concept and design of the larger study. K.I.S., M.G. and A.M. contributed to the design of the current analysis, analysis and interpretation of data, as well as the drafting and revising of the manuscript. N.D. and R.M.N. contributed to the analysis and interpretation of data and critically revised the manuscript for important intellectual content. All authors approved the submitted manuscript for publication and take responsibility for its content.

## Data management and sharing

Data management is supported by the University of Victoria policy and procedure. It is stored at the Institute on Aging and Lifelong Health. Due to the personal nature of the data, only de-identified data are available upon request to the first author.

## Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

## Ethics and consent

Ethics approval for this study was obtained by UVIC/VIHA Joint Research Ethics Sub-Committee (Number: J2014-028) on July 23, 2014. All participants provided written consent, with ongoing verbal consent continually confirmed during the data collection process.

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