TOO LITTLE, TOO LATE:

How we fail vulnerable Canadians as they die and what to do about it

Final Project Report for the Equitable Access to Care Study in Victoria, British Columbia

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We acknowledge with respect the Lkwungen-speaking peoples on whose traditional territory the university stands and the Songhees, Esquimalt and W̱SÁNEĆ peoples whose historical relationships with the land continue to this day.

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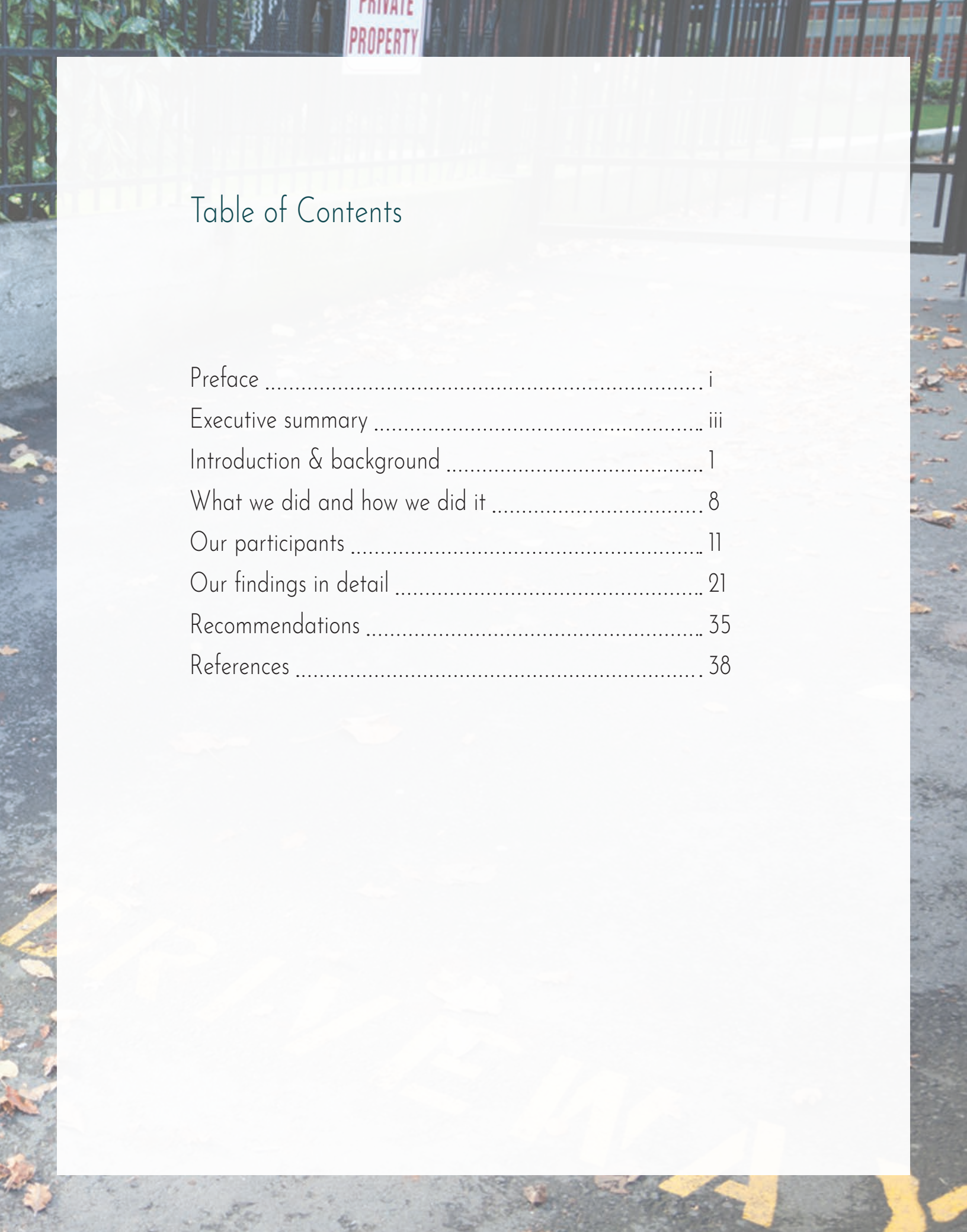

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Preface

In 2014, I was approached by the Palliative Outreach Resource Team (PORT), a group of mainly downtown service providers who were working off the sides of their desks to figure out how to get better palliative care for their inner city clients. One member of PORT, Caite Meagher, a former street nurse, and now home care nurse, had been in touch with me over the years, persistently reminding me about a problem we had identified 20 years ago in a study examining an outbreak of HIV and Hepatitis C among people who use drugs in Victoria. The issues of unjust death frequently emerged in that prior study and I was reminded of my early experiences as a nurse working at the height of the AIDS epidemic and the stigmatizing and horrific deaths I bore witness to.

In many ways, the contexts of care and caregiving in this community have remained unchanged over the past 20 years.. Homeless and barely housed people continue to die at an alarming rate, at half the age of the average Canadian. People using illicit drugs and living with mental illness continue to experience stigma and discrimination preventing access to and quality of care. Legacies of colonization have lasting impacts in the bodies of Indigenous people and the institutions where they access services. Indigenous and non-Indigenous, homeless and barely housed people continue to experience suffering and unmet needs at end-of-life.

In some ways things have changed. Austerity measures have tightened governments' purse strings cutting back on the construction of social housing and funding for health care programs. British Columbia is facing the worst housing crisis in history with vacancy rates in Victoria below the 1% mark. Increasingly, people with advancing illness are forced to rely on unpaid family caregivers. Deaths from the opioid crisis have largely replaced deaths from AIDS in the inner city community, where we now hear about these deaths on a daily basis – something that has exacerbated deep bereavement in the inner city community.

Throughout the research process, our team often critically discussed our focus on quality care at the end of a homeless person's life. Why not focus on quality of care during the entirety of a homeless persons life? Having worked in palliative care for over 30 years I know deeply what the whole-person care approach in palliative care could potentially have to offer. In its focus on quality of life, it is inherently harm reduction and trauma-informed. Palliative practitioners understand and attend to physical, psychological, emotional and spiritual pain.

In our research, people who were criminalized and stigmatized for self-medicating most of their life said this was their first time getting good care. A man with stage 4 cancer told us, *"I don't need to buy drugs off the street anymore, I can call my doctor when I'm in pain."* Ensuring access to palliative care for homeless people with advancing conditions doesn't come at the expense of advocacy for quality care through the lifespan. On the contrary, palliative care teaches us what good care looks like. The real problem we are left with is how to move a palliative approach to care upstream.

In this report, we condense and summarize what we have learned from our research. In the report, you will read stories from people who opened up and shared their lives with us. You will find results and recommendations on how to improve access to and quality of care at end-of-life for homeless and barely housed people. And mostly what I hope is that we use this research to shift policy and practice around end-of-life care for people in our community who are fully deserving of dignified deaths and lives.

Kelli Stajduhar, RN, PhD, FCAHS

Executive summary

For most Canadians, good palliative care is still not a given, despite its many proven benefits that add up to a longer, more comfortable time before death. Access to the services involved, from medical to social to psychological, is uneven across the country and is not universally funded. This report explores findings from a recent research project on equitable access to palliative care in Victoria, British Columbia (BC). Our participants belonged to a vulnerable segment of Canadian society – those in poverty, homeless or barely housed, disabled, racialized, mentally ill, using illicit drugs. To capture this group clearly and without attaching blame or promoting stigma, we have come to describe them as a population who are "structurally vulnerable."

We wanted to find out who these individuals were, how they lived and died, and what we could do to alleviate suffering and loneliness at the end of their lives. The main objectives of the study were to:

1. Provide a detailed contextual description of the experiences of homeless and barely housed individuals in accessing health care services at the end-of-life in Victoria, BC;

2. Identify barriers and facilitators to promoting quality palliative care for this population;

3. Review promising programs and practices; and

4. Develop recommendations for improving access to end-of-life care for structurally vulnerable people.

What we did and how we did it

This study was ethnographic, a kind of research that describes humans in their various cultures. For two years, over 300 hours of observations were conducted with 25 homeless and vulnerably housed people, their support persons (e.g., people they choose to act as family), and service providers. A total of 147 interviews were conducted with these groups as well as key informants including managers, medical directors, executive directors, and policy makers. Interviews with representatives of organizations supporting people at end-of-life across Canada, in the United States, and the United Kingdom supplemented our data as well as community knowledge exchange forums to share preliminary findings, gain feedback, and identify any potential data gaps.

Our findings

Our analysis found that dying participants bore the brunt of all the commonly experienced injustices lived routinely by people who are structurally vulnerable, including stigmatization, criminalization, racialization, and marginalization. Our key thematic findings were:

The survival imperative

Structural vulnerabilities shaped our participants' lives, constraining their opportunities, choices, and decisions. Because of the need to survive, palliative care and even discussions about death and dying were simply absent from participants' everyday realities and the purview of their support persons and community-based service providers.

The normalization of death

People in the street community typically die suddenly from similar overdoses and accidents, making deaths from life-limiting conditions unexpected. Furthermore, participants had witnessed many people in their social networks dying and had often been told that they were also going to die because of their "lifestyle". Often this made end-of-life conversations less serious or significant.

Recognizing the need for palliative services

Identifying those experiencing structural vulnerability who need palliative care is not easy. Participants were diagnosed late in their trajectory and many were not identified as in need of palliative care until they were actively dying. Many had experienced a lifetime of poor treatment, stigma, and discrimination in health care settings, resulting in avoidance and distrust of mainstream health care institutions (e.g., hospitals) and medical professionals.

Silos to bring down, cracks to fill

Structurally vulnerable people must navigate multiple systems to get what they need, like social assistance, shelter and housing, and food banks. This became exacerbated at the end-of-life. Lack of continuity and consistency in palliative care service providers created barriers to care for this community, where relationships of trust are paramount.

Risk management as a barrier to aging in place and dying at home

Home care workers and nurses become necessary to the palliative response as people's needs become more complex. Some participants were housed in single room occupancy hotels, supportive housing facilities, or shelters that were deemed unsafe for home support and/or home care nurses to attend. A lack of appropriate, affordable, and adequate housing, combined with risk management policies, meant that people could not age in place and were moved (most often into acute care) as their medical needs increased or as they approached the end-of-life.

A bereaved community, supporting workers and "chosen" family

This is a world of unmet needs, multiple losses, persistent grief, and vicarious trauma. While workers sought and received support in their organizations and had their own coping strategies, the mechanisms for providing support to those who care for dying people are inadequate, given the magnitude of loss and injustice witnessed and experienced. Informal support networks (communities or individuals who looked out for the person), street family, and occasionally biological family members, were present in the lives of many participants, yet support people often had complex relationships with our participants and had their own health issues.

Justice at the end-of-life for some

By and large, when people received a "legitimate" (palliative) diagnosis and were assigned to service providers who had a palliative orientation and orientation to the social determinants of health, services came around them quickly and efficiently, and their end-of-life experiences went well.

Recommendations

1 Address barriers in formal health care settings that prevent people experiencing structural vulnerabilities from receiving diagnosis, treatment, support, and care.

- Create educational opportunities for health care providers to learn about barriers to care for structurally vulnerable people and how they can best support them during their end-of-life experiences. This should include education based in principles of trauma and violence informed care, cultural safety, and harm reduction.
- Address policies (e.g., behavior policies, abstinence policies) that result in structurally vulnerable people avoiding, being turned away from, and leaving healthcare settings early without access to quality care, information, or follow-up.

2 Integrate palliative approaches to care where people experiencing structural vulnerability live and die.

- Promote knowledge sharing, coordination, and continuity between health care (e.g., acute care, palliative care, home and community care) and inner city services (e.g., housing, shelters, and health services) to address social determinants of health as a precursor to good palliative care.
- Support health care organizations to develop policy and strategies to mitigate risk and facilitate access to care in community settings (e.g., reviewing no-go building lists; housing worker or support people introduction/accompaniment; exploration of perceived versus real risk).
- Create accessible, non-medicalized education and resources for housing, health, and support persons working closely with structurally vulnerable people. This should include education on palliative approaches to care, supporting palliative health and social needs, navigating the palliative care system, and legal and financial resources available at end-of-life.
- Build on other Canadian models to develop mobile palliative care services with access to nurse and physician support for complex care needs, to coordinate, communicate with, build capacity, and educate people experiencing structural vulnerability, their support persons, and service providers involved in end-of-life care.
- Consider creating appropriate space in existing housing units for people to go when they need 24/7 support/health care but do not need to be in acute care.

3 Support non-traditional families (e.g., street family, inner city workers) and include them in decision-making processes and care strategies.

- Address assumptions and policies in health care and housing organizations (e.g., privileging of biological family, guest policies) that prevent non-traditional family from caring for their loved ones at end-of-life.

- Accept and embrace that the classic divide between workers and clients is no longer the rule, as workers are in de facto family roles, coping with deep bereavement, and often in housing crisis and living in poverty themselves.

- Provide bereavement support for workers and support people to recognize and show respect for their important caregiving role. This may take forms beyond individual support to collective action against unjust and untimely deaths.

- Conduct further research exploring the roles of non-traditional families as caregivers in structurally vulnerable communities.

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Benny, 75, wound up in hospital after his severe medical issues – including prostate cancer – became too much for his housing provider. He was there four months, transferred to a transitional care unit for three months and then finally was discharged due to drinking and aggressive verbal behavior. He was assigned to a case management team that arranged for Benny to live in a motel, but after the owners raised the rent, he moved to a homeless shelter. He died after another move into supported housing. In the last two-and-a-half years of his life, Benny moved five times and spent more than half a year in hospital.

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Sammy was dying with late-stage COPD (chronic obstructive pulmonary disease) and schizophrenia. He lived in supportive housing, a level of accommodation in British Columbia that offers light housekeeping and some meals. Sammy had a mental health case worker who was looking for other housing arrangements, but he did not qualify for assisted living, which provides personal care and 24-hour professional supervision. Sammy, at age 56, ended up dying alone in supportive housing, in a pool of his own vomit with his oxygen mask hanging at his side.

Who gets to have a "good" death?

Nobody likes to think about their own death, but we all naturally wonder how and where it will happen. We hope for a peaceful, dignified, pain-free death, surrounded by loved ones in comfortable, familiar surroundings. This fits with our ideas of what death and dying *should* look like and where palliative care – the prevention and relief of suffering associated with end-of-life illnesses – *should* be available.

For most Canadians, however, good palliative care is still not a given, despite its many proven benefits that add up to a longer, more comfortable time before death. Access to the services involved, from medical to social to psychological, is uneven across the country and is not universally funded. Even though Canadians almost unanimously support palliative care as a concept, that is what it remains: an idea that only becomes reality for fewer than half the people who might benefit. The reality is that family members take care of most dying Canadians. Legions of invisible, unpaid caregivers support the end-of-life care system, such as it is, in this country.

In a recent research project on equitable access to palliative care in Victoria, BC, we followed participants including Sammy and Benny, who never heard of palliative care and did not have family ready to take them in. Our participants belonged to a vulnerable segment of Canadian society – those in poverty, homeless or barely housed, disabled, racialized, mentally ill, using illicit drugs – who often die as they live, with needs unmet, in dirty, sparsely furnished rooms or even the street. The vulnerabilities and stigma they experienced daily in life chased them into often invisible and painful deaths.

In a sad paradox, we found that the closer to death the participants drew, the more likely they were to lose whatever housing they might have had, whether it was a rent-subsidized apartment, a room in a boarding house or a bed in a shelter.

The participants were also dying far younger on average – in their late 50s – than the rest of Canadians, whose longevity has been increasing. Just when people in the general population are usually experiencing the peak of their careers, the highest salaries they will likely ever earn, and looking toward a long, happy retirement, our participants' lives were ending. Their complicated needs left their terminal illnesses undiagnosed and palliative care not offered. We found that sometimes access to minimal palliative care was possible, but it was always too little, too late.

Being "hooked in" to the social welfare system in their daily lives did not help our participants die anything close to good deaths; they were nobody's priority. In fact, the only reason some received palliative care at all was because they happened to be in the study. By the luck of the draw, they went on the radar of health professionals who otherwise would not have recognized their conditions were terminal.

We wanted to find out who these individuals were, how they lived and died, and what we could do to alleviate suffering and loneliness at the end of their lives. We found that they required a different approach to accessing palliative care and that a new approach would not require huge influxes of funding. But it does mean changing how we think about poverty and about what happens when some lives are considered more valuable than others.

Our research team spent more than 300 hours with 25 homeless or barely housed people in Victoria, BC over a two-year period. In that time just over half the participants (13) died; once the study ended we were unable to continue following the remaining participants.

We conducted interviews, attended trips to medical appointments (sometimes doing the driving), and made many observations of interaction between health and social care providers. This group included 15 physicians and 13 nurses. Participants were referred to our study by professionals working in inner city health, housing, and service agencies who anticipated that their clients would die within a year because they were living with chronic and terminal conditions.

We also talked to their support persons (friends, "chosen" family – those friends designated as family) and service providers, adding up to almost 150 interviews. Researchers conducted individual interviews, held focus groups, gathered for three community forums to share findings and looked at promising palliative program models in other jurisdictions.

We found that participants were subjected to the same common injustices in their dying as they were in their daily lives, including stigmatization, criminalization, racialization, and marginalization. This meant a lack of access to what average Canadians take for granted, from comfortable, (mostly) affordable housing to the services, programs and policies that keep us physically and emotionally healthy. Those services can include palliative care, in many forms.

The World Health Organization (WHO) defines palliative care as "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."[1] In Victoria, that translates into a wide range of palliative services. They include: home health care visits (nurses, home support workers, counsellors, volunteers); inpatient hospice and palliative care services, including respite for the dying person and family; home visits by professionals offering emotional support to caregivers; and help with everything from writing a will to journaling about grief. For those dying on the margins of society, almost none of this ever happens. Although the WHO recognized access to quality care at the end-of-life as a human right last year, access is by no means equitable.[1]

The study shows how the participants' focus on simply surviving the day meant that they could not seek out or access palliative care when it was needed and that palliative care was not consistently available for them. Early death was a given in their world, seen as an inevitable result of their "lifestyle choices." End-of-life diagnoses went unmade; participants fell through the cracks of a siloed care system; risk management policies prevented care workers from entering participants' residences, preventing their aging in place and dying at home; their communities – friends, those acting as family, long-term care workers – suffered bereavement without support or even acknowledgement of their loss.

We found that some health care and support workers provided good, compassionate end-of-life care beyond their job descriptions. But that was the exception rather than the rule. Just as they do in the hard-scrabble daily existence of marginalized people, prejudice and judgment often got in the way of palliative care being offered or available as they neared death.

Readers will find many of the recommendations offered in this report arise from the observation that the attention and resources brought to homeless and barely housed people through study participation itself prompted improvements. This is good news; massive cash injections and program overhauls are not needed. Rather, developing an orientation to palliative care that is built into and bridges existing programs will make a big difference in the living and dying of Canadians with multiple barriers to good health and safe housing.

To capture this group clearly and without attaching blame or promoting stigma, we have come to describe them as a population who are "structurally vulnerable."

Who are "structurally vulnerable" people?

We often picture "the homeless" as those relatively few, visibly homeless people (usually men) asleep on flattened cardboard in alleyways or hidden from view in emergency shelters. But homelessness is complicated, defined along a continuum, and encompassing those who do not have stable, permanent homes or housing that fits their needs. Having part-time, temporary or low-paying work can lead to homelessness, as can a lack of supports for serious, persistent mental illness. In Victoria, housing costs are among the highest in the country, with rents well over $1,000 a month on average.[2] Those living on fixed incomes (old age pensions and social assistance payments that don't increase) can find they must choose between paying rent and buying groceries. Those we might call barely housed may be one cheque away from losing their apartment, including hidden legions of seniors who have no other income and no family in town to help them.

Structural vulnerability can be thought of as what happens to people who are forced to occupy the lower ranks of our social hierarchy, subjected to the policies of those with far more status and power.[3] Structural vulnerability moves away from the belief that a person is to blame for their dire circumstances and suggests that the problem is about external forces (e.g., poverty, homelessness, criminalization, racialization, colonization, etc.) and assumptions that a single individual is at fault. Structural vulnerability is dynamic, meaning it can alter a person's life and can also change itself as a response to a new environment (e.g., policy or health care reforms, economic restructuring).[4]

Connected to this idea are the "social determinants of health," or those factors that influence our overall wellbeing.[5-6] A person's income, education level, employment and food security, along with their gender, race, and disability status, interact to affect health. People who are structurally vulnerable – living in poverty, homeless or barely housed, racialized, experiencing stigma because of mental illness or substance use – face major barriers to access and quality of care.[7] They have higher rates of disease and poorer health status compared to a more privileged, higher income, and securely housed population.[8-9]

Homeless people have more aging-related conditions compared to those who have stable homes and are decades older.[10-12] They are almost 30 times more likely to have infectious diseases such as Hepatitis C.[13] Rates of chronic illness such as heart disease and cancer are similarly high.[13] As we saw in our study, people who are homeless or unstably housed are reported to have half the life expectancy than those in the general population.[14] For example, in our study, males died at roughly twice the rate of other men in their age range.

Death and dying in this population occur in some palliative care settings. But more likely they will die in hospital or alone, on the street and in vehicles, or in shelters or transitional housing.[15-19] Workers who are highly compassionate may care for them, but they have limited palliative care training, knowledge, and access to resources to ensure quality end-of-life care.[20]

While good care at life's end is clearly important, people who are homeless or unstably housed, who live with mental health and addictions issues and other structural vulnerabilities generally do not line up with the profile of patients typically admitted to hospices or palliative care units.[21] Policies and regulations that are customary in most institutions (e.g., fixed visiting hours; substance use policies) only worsen the effect of the myriad barriers that vulnerable people face in accessing services that would promote quality end-of-life care.[17, 22, 23] Traditional ideas of palliative care as delivered within specialized contexts (e.g., hospice settings or palliative care units) are generally not designed to meet the needs of vulnerable populations. The assumptions that palliative care is based on the presence of safe and secure housing, family supports and income for ancillary costs associated with dying don't apply to this population.


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What we set out to do

The main objectives of the Equitable Access to Care (EAC) study were to:

- Provide a detailed contextual description of the experiences of vulnerable individuals in accessing health care services at the end-of-life in Victoria, BC;
- Identify barriers and facilitators to promoting quality palliative care for this population;
- Review promising programs and practices;
- Develop recommendations for improving access to end-of-life care for structurally vulnerable people.

What we did and how we did it: the methodology[a]

The EAC study was ethnographic, a kind of research that describes humans in their various cultures. Our work was informed by equity and social justice perspectives[24] and we deliberately set out to generate knowledge that would inform change in the ways in which care for structurally vulnerable people at the end-of-life unfolded. These approaches orient researchers to look at the structural conditions that shape and contribute to the development of inequities. Health inequities are those differences in health or access to health care that result from structural arrangements that can be changed.[25, 26] Ethnography focuses on studying social contexts; in our case, this meant the social structures, processes and conditions that shape access to care at the end-of-life. The research approach relies primarily on interviews and observations to provide rich, contextualized descriptions of people's lived experiences.

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a For a full discussion of the research methodology and other publications please see https://www.uvic.ca/research/groups/peol/current-research/equitable-access/index.php

Primary data were collected in two ways:

Participant observation: Over 300 hours of observations were conducted with 25 homeless and vulnerably housed people, their support persons (e.g., people they choose to act as family), and service providers over a two year period. The researchers met participants where they lived, in the places where they accessed services, recording detailed field notes about their experiences. Sites of participant observation included living spaces (e.g., market housing; supported housing; shelters and transitional care spaces), at medical appointments (e.g., doctors' offices, hospital appointments), in drop-in spaces (e.g., food banks, clinics), and on the street.

Interviews and focus groups: A total of 147 interviews were conducted, including multiple interviews with structurally vulnerable people, their chosen support persons, service providers, and key informants including managers, medical directors, executive directors, and policy makers.

In addition, our research was informed by:

Interviews with representatives of organizations supporting vulnerable people at end-of-life: Through a systematic internet search, we identified 34 potential programs offering care to vulnerable and marginalized populations and that had websites published in English. Program representatives were in Canada, the United States, and the United Kingdom. Websites were further reviewed for content specifically targeted to palliative care for vulnerable and marginalized populations, leaving a potential 22 programs/services. Email contact was initially made with all 22 organizations and follow-up telephone calls were made up to five times for non-responders. In total, 11 organizations responded to our request for a telephone interview. Of the 11, one was excluded as they were not an organization providing services. A total of 10 representatives were interviewed by telephone following a structured interview guide.

Knowledge exchange forums: We held three knowledge exchange forums over the course of the study to share preliminary findings, iteratively gain feedback from community members, and identify any potential data gaps. The events served to validate findings with the wider community, set the stage for service planning and uptake of research findings, and inform next steps. Community events were targeted to three audiences: (a) people with lived experience of poverty and homelessness, and the inner-city workers who serve them; (b) health and social care workers and managers from inner city agencies; and (c) directors, decision and policy makers from government, health authority, and not-for-profit agencies.


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Our participants

Structurally vulnerable people

Our interview and observational data revealed our participants had histories of, and ongoing experiences with, racism (racialization), colonialization (e.g., Canadian residential schools, The Sixties Scoop), trauma and violence, which may have occurred in institutions (e.g., prisons, hospitals) and earlier homes (e.g., family home, foster care); stigma associated with mental health issues (not necessarily diagnosed); stigma and criminalization of past or current substances use (e.g., illicit drugs, alcohol, including illicit alcohol); and criminal justice system experience. Many of our participants had mobility and physical barriers, often including a physical disability, and faced significant transportation barriers. They had health literacy challenges and behaviour issues in some cases.

All of our participants were homeless or barely housed, fitting the Canadian definition of homelessness (e.g., unsheltered; emergency sheltered; provisionally accommodated; or at risk of homelessness).[27] All were living in poverty (e.g., on social assistance, People with Disabilities benefits, government pension, or receiving no income) and often supplementing income with precarious work (e.g., recycling or binning, panhandling, sex work); often socially isolated and estranged from family and potentially geographically isolated; and often didn't know where their next meal was coming from. Table 1 outlines some additional key characteristics of our structurally vulnerable participants.

Table 1. Key Characteristics of Structurally Vulnerable Participants (n=25)

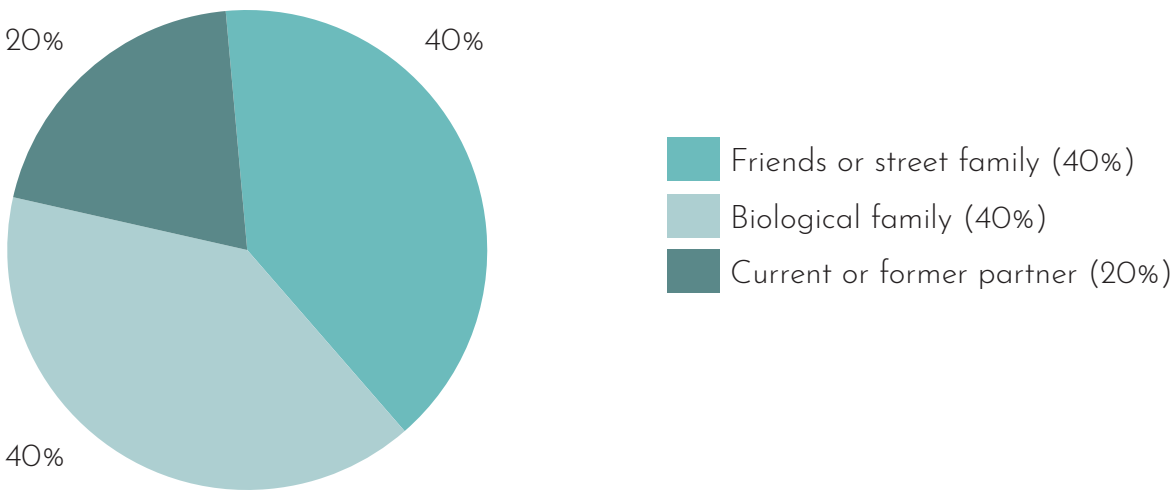
Characteristic	Number of participants
Demographics	
Gender	16 men 9 women
Age range	19-81 years (average = 59 years)
Race/ethnicity	13 White/European settler 8 Indigenous 1 African Canadian 3 did not respond
Marital status	9 divorced or separated 8 single 3 married/common law 2 widowed 3 did not respond
Level of Education	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 2 elementary school or less
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.)
Main source of income	13 Provincial Disability Benefit 6 pension 1 social assistance 1 employment assistance 4 did not respond
Sexual orientation	20 heterosexual 2 LGBTQ 3 did not respond

Characteristic	Number of participants
Health status	
Primary life-threatening condition (self-reported)	15 cancer 3 diabetes (uncontrolled) 2 chronic obstructive lung disease 5 unaware of primary diagnosis
Co-morbidities (self-reported)	10 arthritis 6 cardiovascular disease 6 Hepatitis C 2 HIV/AIDS
Mental illness	7 yes, self-reported 7 yes, identified by health provider (including undiagnosed, but suspected)
Substance use	
Self-reported use of illegal drugs	12 yes 13 no
Substance use (self- reported)[b]	16 tobacco/alcohol 11 opioids 10 cannabis 3 powder cocaine
Primary access to medical care	18 inner city health clinic or physician office 7 acute care hospital
Died during the research process	13
Palliative care access	5 access to palliative care > 2 weeks before death 5 access to palliative care < 2 weeks before death 3 no access to palliative care
Place of death	8 supportive housing 5 palliative care unit

b 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.

Support people

Twenty-five support people, who often faced difficult circumstances of their own, participated.[c] The support people included 10 friends or street family, 10 biological family, and five current or former partners. There were 11 men and 14 women aged 35 to 71, with an average age of 50. Twelve identified as White/European settler and six as Indigenous. Sixteen identified as heterosexual and two identified as gay or lesbian. Nine were single; six were married or living in a common law relationship; and three were divorced or separated. Five had less than a high school education; two identified graduating from high school; and 10 had some college or university education. Their housing status was predominantly living in market rental (11), while three were living on the street, two lived in social or public housing, and two lived in a purchased home. Six identified their main source of income as employment income; four received social assistance; four received pensions; three were on provincial disability benefit; and one identified "other." Support people were also living with life-limiting and other health conditions, including five with arthritis, four with Hepatitis C, three with cardiovascular disease, three with COPD, one with cancer, one with diabetes, and one with HIV/AIDS. Five self-reported as living with a mental illness. Table 2 outlines some additional key characteristics of our support person participants.



c Demographic data does not equal 25 because data were missing in the following categories: age, ethnicity, marital status, level of education, housing status, source of income and sexual orientation.

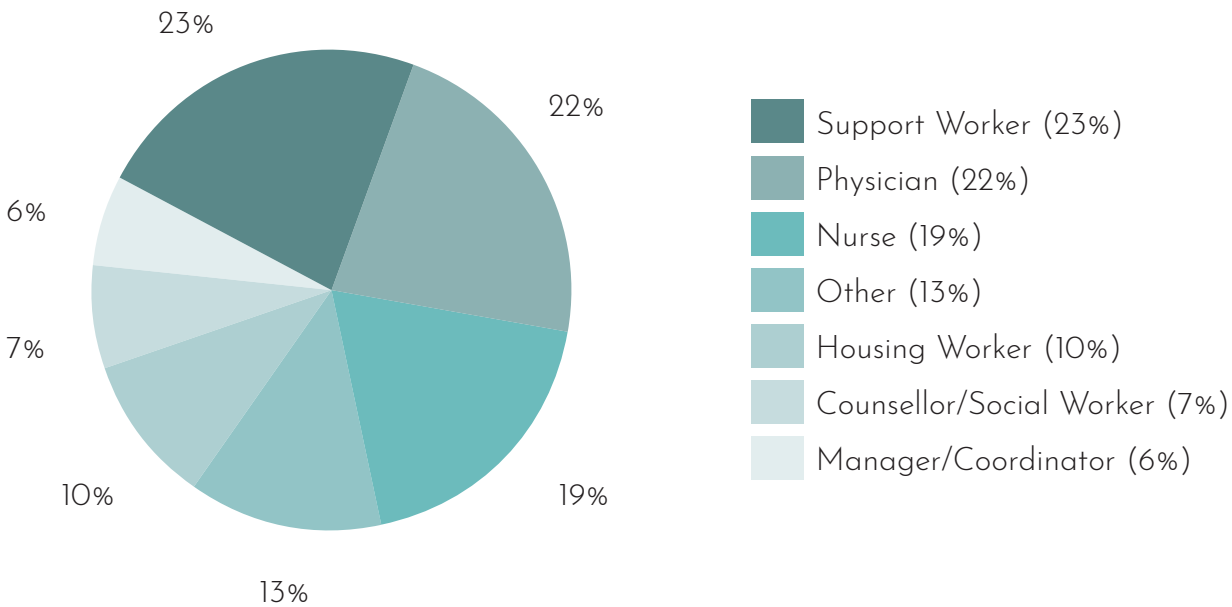
Table 2. Key Characteristics of Support People (n=25)

Characteristic	Number of participants
Demographics	
Gender	11 men 14 women
Age range	35-71 years (average = 50 years)
Race/ethnicity	12 White/European settler 6 Indigenous 7 did not respond
Marital status	3 divorced or separated 9 single 6 married/common law 7 did not respond
Level of Education	2 completed a post graduate degree 1 completed university 1 attended university 1 completed a college diploma 5 completed some college (including trade school) 2 completed high school 4 completed some high school 1 completed middle school 8 did not respond
Housing status	2 purchased home 2 social or public housing 11 market housing 3 homeless (e.g., shelter, boat, hospital, etc.) 7 did not respond

Characteristic	Number of participants
Demographics	
Main source of income	3 Provincial Disability Benefit 4 pension 4 social assistance 6 employment income 1 other 7 did not respond
Sexual orientation	16 heterosexual 2 LGBTQ 7 did not respond
Relationship to structurally vulnerable person	10 friend/street family 10 biologically family 5 former or current partner
Health status	
Life-limiting conditions	5 arthritis 3 cardiovascular disease 3 chronic obstructive lung disease 1 cancer 1 diabetes
Other conditions	1 HIV/AIDS 4 Hepatitis C 5 self-reported mental illness

Service providers and key informants

Sixty-nine service providers participated:[d] 41 women, 25 men and two transgender people. Many had a university degree (n= 23) and others had a post-graduate degree (n =6), attended university (n = 5), obtained a college diploma (n = 5), attended some college (including trade school) (n = 4) or completed some high school (n = 1). This group represented a range of jobs including 16 outreach or support workers, 15 physicians, 13 nurses, seven housing workers, five counsellors/social workers, four managers/coordinators, and nine "other." Two service providers had been in their role for less than a year; 20 had been in their role for one to five years; six for six to 10 years; five from 11 to 15 years; two from 16 to 20 years, and five for 20s or more. Interviews with 20 key informants were done, including managers, medical directors, executive directors, and policy makers, representing 10 health, housing, social, and palliative organizations.



d Demographic data does not equal 69 because data were missing in the following categories: gender, age, ethnicity, and education level, and length of time in current role.

"People [experiencing structural vulnerabilities] are just so busy living in the moment and surviving."

Our findings in detail

As noted above, our analysis found that dying participants bore the brunt of all the commonly experienced injustices lived routinely by people who are structurally vulnerable, including stigmatization, criminalization, racialization, and marginalization. We report on those themes that focus on the context of palliative care and are far less visible in the research literature.[e]

The survival imperative

Structural vulnerabilities shaped our participants' lives, constraining their opportunities, choices, and decisions. They all lived in poverty, which could involve inadequate housing, stigma associated with their substance use and mental illness, and racism. These intersecting oppressions limited their freedom, the ability to obtain and maintain adequate health and well-being, and their capacity to seek out and access palliative care. This inner-city physician describes how poverty determines everything:

Poverty is the huge, overlying thing, and that just manifests in any number of ways. So, it's as simple as food, telephone access, taxi rides, being able to buy support stockings, accessing a cane, getting to the Red Cross to pick up supplies or navigating how to do that without a telephone or without friends. It's all those pieces. It can be as simple as people not having a pen for us to write on something. I have been in homes where you literally have to stand up because there is nowhere to sit down.

Often our participants would have no money, food, or transportation to meet their basic survival needs, let alone the extra requirements at the end-of-life (e.g., getting to medical appointments; equipment). When access to immediate needs for shelter and food were lacking, including routine access to alcohol or drugs in the context of addiction, finding palliative care services was not a priority. For example, our fieldnotes reflected that getting enough food to eat was an everyday challenge for Amber: *"It became clear that her focus all day, every day, was simply on finding food."*

Because of the need to survive, palliative care and even discussions about death and dying were simply absent from participants' everyday realities, despite their declining health. Their awareness of and knowledge about the palliative care services available to them was either minimal or non-existent. Neither did many of the community-based service providers know what a palliative approach was or what it could offer their clients. The full benefits of a palliative approach were not often seen, as late diagnosis and a shortened trajectory meant less time to intervene in the physical, social, emotional and spiritual needs of the person.

Formal health care providers rarely acknowledged the everyday requirements that participants need to survive (i.e., food, shelter, income) and how this might influence their ability to have palliative care. One research assistant's field notes documented the immense amount of work it took for Felix, a 54-year-old man with lung and liver cancer, to make, and stay for, a hospital consultation for his advanced liver cancer:

Between the time that Felix found out about the appointment and when he was supposed to go, he relapsed and was kicked out of his housing and had to move to a shelter downtown. To find out the time of the appointment, he had to get another worker to phone me, because he no longer had the information. Then he had to get himself to the appointment. If I wouldn't have been in the picture, he would likely have had to take the bus, meaning he would have had to come up with bus fare ($5 return), or he would have had to walk. He had to miss lunch at the [shelter] and then he had to sit inside for over an hour and a half, during which time he was unable to smoke. He didn't really understand what the appointment was for or its level of importance, which made it difficult for him to make an informed decision about leaving or staying. When he tried to get information from the people at the desk, he was very polite, but they seemed to have the attitude that people just had to wait and that's just the way it is in the hospital.

e Participant names have been changed to protect their identities.

For some health care providers, paying attention to the social determinants of health seemed to fall outside their scope of practice, resulting in palliative care needs sometimes not being addressed. The most common barrier raised by participants was the cost of transportation to and from their many appointments. Without access to vehicles and friends who had vehicles and could drive them, participants relied on public transportation. The farther they had to go, the more it cost. The challenge of public transportation was exacerbated as people became sicker and their health and mobility declined. George, a 79-year-old Caucasian man who was living with advanced cancer and kidney failure, told us:

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?! It's ridiculous to put the hospital out there! So the only way you can get to it is by a vehicle, which is absurd!

We found that only by addressing deficits in such things as housing, food security, income, and transportation could our participants get quality care at the end-of-life. Housing emerged as an essential determinant. Much of the work that service providers did was to help people maintain their housing, advocate that people get care in their housing, or facilitate the moves of people and their belongings. Access to care was eased when research assistants drove people to appointments and when workers in community and hospitals provided taxi vouchers or bus tickets to clients or helped them apply for bus passes. It helped when health care services could come to the client or when services were offered where the participant already was. Non-profit organizations often tried to mitigate the ancillary costs of dying – money for special diets, adult incontinence products, equipment, and other medical supplies not covered by Medicare or palliative benefits – but this was inconsistent and based on availability.

The normalization of death

Participants had witnessed many people in their social networks dying and had often been told that they were also going to die because of their "lifestyle." This reinforced the myth that they were to blame for their situation rather than showing an understanding of the structural markers that caused discrimination against them. This discourse resulted in a certain "normalization" of death in the community and a sense that marginalized people pay a death penalty for being in their situation.

At the time of our study, British Columbia was seeing, and continues to see, an unprecedented number of overdose deaths connected to the opioid crisis. While death in the street community is prevalent, people typically die suddenly from similar overdoses and accidents, making deaths from life-limiting chronic conditions such as cancer or liver or kidney disease, unexpected. A manager of transitional housing explains:

We assume that most of the people we work with in housing are close to end-of-life. That's their health, coupled with their lifestyle or behaviours around drug and alcohol use. That combination [means] they're probably quite close to risk around end-of-life. So, it's never a shock.

When participants were told they were on a palliative trajectory, they often did not react with the same concern that others with differing life experiences might. For example, Sherry had been told multiple times that she was at risk of dying because of her addictions. After being diagnosed with metastatic cancer, she did not take the medical system, her diagnosis, or the care she required, seriously. It was not until she was in severe pain that Sherry was convinced by her service provider to seek help.

Health providers try to warn their clients about potential fatal outcomes of their conditions and lifestyles, which often had the effect of making end-of-life conversations less significant. The normalization of death and death warnings, combined with the focus on survival, meant that palliative care stayed off the radar and was relatively invisible as a result.

"Everybody in this community is at risk of dying."

"I'm not trained to talk to somebody about dying. We don't really treat people like they are dying … I guess we do, but … when we're interacting with them, we don't interact with them like they are dying people."

Recognizing the need for palliative services

Identifying those experiencing structural vulnerability who need palliative care is not easy, as our participants taught us. They were diagnosed late in their trajectory and many were not identified as in need of palliative care until they were actively dying. Much of the care and support provided to participants came from outside the health system. Outreach, housing, mental health and harm reduction workers are a primary point of contact for people experiencing structural vulnerability. Despite seeing high rates of death in the population, however, many "social care workers" were understandably unprepared when it came to: identifying who could benefit from a palliative approach; having conversations about death; understanding a person's diagnosis and trajectory; understanding how the palliative care system works; or understanding their own feelings of loss and grief. A housing support worker said:

I'm not trained to talk to somebody about dying. We don't really treat people like they are dying … I guess we do, but … when we're interacting with them, we don't interact with them like they are dying people. We interact like they are an unwell person. So it could be that it's more the staff's reluctance due to our inexperience. If we were trained in hospice and palliative care, we would know how to have these conversations. But it's awkward.

A lack of trust in the health care system and its providers, and prior experiences of stigma and discrimination meant that participants avoided mainstream health and medical care until it was absolutely needed. Health care needs often went unaddressed, including needs for palliative care. George refused all but one home support worker because he felt stigmatized by them. When we asked George what was good about this particular home support worker's care, he responded:

Well, he was efficient and didn't make a judgment on how messy the place was … I live like this and I know I'm a mess. Periodically I clean up, but I don't like to be judged on that, you know?

The impact of racialization and colonialism played a large role in the lives of the Indigenous participants. Lewis was a 60-year-old Indigenous man who had grown up in poverty, had attended residential school and had a history of illicit drug use. A lifetime of negative institutional experiences meant that Lewis avoided the hospital. When he did go to hospital with excruciating pain, he was diagnosed with advanced cancer. Treatment was no longer an option for him. An Indigenous outreach worker explained avoidance of care in First Nations populations:

Historically, they've [indigenous people] been neglected, ignored. When they go to the hospital they're not going to feel like anybody really cares about them anyway. So they're going to be really quiet … they won't ask the questions. And so the nurses or the doctors, the hospital is really lucky 'cause they don't have to do anything now. "Okay, we put a Band-Aid on that, now away you go."

Historical and ongoing experiences of discrimination and neglect can manifest in Indigenous people's silence during health care interactions resulting in care needs being unrecognized and unmet. Recognizing the need for palliative care services is rendered invisible in these circumstances.

Not identifying people who could benefit from palliative approaches to care has several consequences. Unnecessary emergency care and acute care admission occurs, physical symptoms such as pain and breathlessness go unmanaged, and as with some of our participants, end-of-life and dying occurs in a less than humane manner.

Silos to bring down, cracks to fill

Structurally vulnerable people must navigate multiple systems to get what they need. This became exacerbated at the end-of-life, when coping with their declining health was added to the list. While community-based service providers are working hard to provide support and care to their clients, working across systems (e.g., housing, income, health care, and palliative care) to promote integrated care between and across systems was challenging.

Yet, in relation to providing palliative approaches to care, we found that when people are identified as having palliative care needs, the limited services that are available, and the agencies that support them, tend to come around people quickly and collaboration among health and social service providers improves dramatically. We saw some people receiving good palliative care where they lived. But more often, structurally vulnerable people were transferred out of their community when their care needs got too high. Organizational, regulatory, and policy barriers, including risk management policies and staffing capacity in shelters and housing facilities, meant people went to hospital when they were dying. This resulted in the misconception by managers and workers that palliative care happens in a separate domain from housing, shelter, and other social services. This housing manager takes us through how decisions are made about whether a person needs the "next level of care:"

We talk about the teams that are supporting them. Is [home support] coming in? How often are they coming in? Where are we at with our care for that person? Generally, the people that are close to end-of-life, are people that we would then move to the hospital. Or people that can no longer get out of bed or that can no longer call for help … They go to hospital … This sounds really bad, but we ask [ourselves], "will they be alive the next day?" … Because we have no staff here in the evening, we have security at the desk. If somebody was in trouble, we'd definitely call an ambulance. But we don't have somebody that goes and does checks and that kind of thing. Now having said that, we have had a couple of people where we have had the security go up and check on them during the night when we were trying to call the ambulance to take them to hospital. Mostly, they don't want to go … And then those people who go to the hospital, more often than not, they don't come back to us.

As we heard in this interview, housing managers and workers are often going above and beyond, doing what they can to keep people housed. However, palliative care and the process of death were often perceived as outside their domain.

"This is a supported housing building so we are limited around what we can provide around medical support. We don't have nursing staff. We don't have medical alerts. We are not set up that way."

"Even though there is absolutely no safety concerns, there is judgement that is being passed that says, 'I do not work with someone like that.'"

Risk management: a barrier to aging in place and dying at home

A lack of appropriate, affordable, and adequate housing, combined with risk management policies such as those described below, meant that people could not age in place and were moved (most often into acute care) as their medical needs increased or as they approached the end-of-life. Some participants were housed in single room occupancy hotels, supportive housing facilities, or shelters that were deemed unsafe for home support and/or home care nurses to attend. While we heard that the health authority had a list of restricted buildings for home care nurses, there were inconsistencies as to which buildings were, in fact, "no go". When buildings were flagged as a safety risk, workers in those buildings used work-arounds such as using their own relationships with individuals in health care; telling their clients to say things on the phone to minimize perceived risk; or meeting or accompanying the home care nurses or home support worker to the first and/or subsequent visits.

Because housing organizations have minimal staff and most are not trained or permitted to provide personal care, dying people depend on health service providers (as opposed to unpaid, invisible, familial labour) at the end-of-life. As people's needs become more complex, home support workers and home care nurses become necessary to the palliative response. Yet, institutional risk management policies and 'no-go' building designations resulted in people not being able to die where they wanted, surrounded by familiar providers and support people they trusted.

Participants told us that their clients had home care services discontinued even when housed because of safety policies that prevented care from being delivered in settings deemed risky (e.g., overcrowded, where cigarette smoke, drugs, or drug-use equipment was present, or where violent incidents had occurred). Jonathan, a housing worker, implied that such risk management policies stem from and reinforce structural stigma that constrains access to care even when actual risks were negligible:

> *A lot of folks that we house, drink and use whatever form of substances. There's a lot of kickback from [home support services]. "I'm not going to go into a place where there's smoke. I'm not going to go into a place if there's an open bottle of alcohol. I'm not going to go in." There's a lot of judgement and stigma. Even though there is absolutely no safety concerns, there is judgement that is being passed that says, "I do not work with someone like that."*

Exacerbating vulnerability, in some cases, care was completely restricted except where individual providers went against institutional policies to provide care "under the grid". Some home care nurses, for example, were more willing to negotiate safety risk to help access to care; others had reasons to be strict. This home care nurse explains the bigger risk should she choose to bend the rules:

> *If we went in and it was a no-go [building], if it was on the list and there was an incident, then we might not be covered by WCB [WorkSafeBC] I've been told that specifically by a manager … I was told we wouldn't be covered by WCB.*

We observed many instances of housing workers going "above and beyond" their job descriptions in effort to keep their dying clients in the community, including doing personal care and providing medications. Going against such policies also put these providers at risk themselves because they were going against their employer's policies; many experienced distress and frustration as they bore witness to gaps in care, inequities, and injustices:

> *Yeah, [I feel] anger and frustration and disappointment and resentment, all those kinds of negative feelings. And then, a little bit of guilt. Like here is somebody [who is dying] who's somebody's mother, daughter, sister, your client. You've known them forever and they're getting substandard care and you feel really shitty that you can't seem to make a difference. Yeah, you can't seem to change the system.*

Risk management policies, while put in place with good and reasonable intentions, resulted in major barriers to accessing needed palliative care. Combined with decreasing mobility and increasing physical decline at the end-of-life, these policies served to amplify structural vulnerabilities, social isolation, and marginalization.

A bereaved community: supporting workers and "chosen" family

This is a world of unmet needs, multiple losses, persistent grief, and vicarious trauma. The service providers in our study felt distress, frustration, and burnout. The inner-city nurse who found Sammy, who had died alone in his own vomit, told us:

I think the thing that really impacted me was to come in and see him there in the apartment alone and know that he just had been alone and not knowing whether he had struggled or not… I mean part of it is just an existential, just about dying. That's always sad. It's a time at the end of your life when I think it brings into view/contrast the things that are there and that aren't. The haves and the have nots become really amplified.

While workers sought and received support in their organizations and had their own coping strategies, the mechanisms for providing support to those who care for dying people are inadequate, given the magnitude of loss and injustice witnessed and experienced.

Service providers are recognizing and pushing back against structural inequities within and outside their organizations, fighting to improve care for not only their own clients but against stigma and discrimination that is pervasive and persistent in health care.

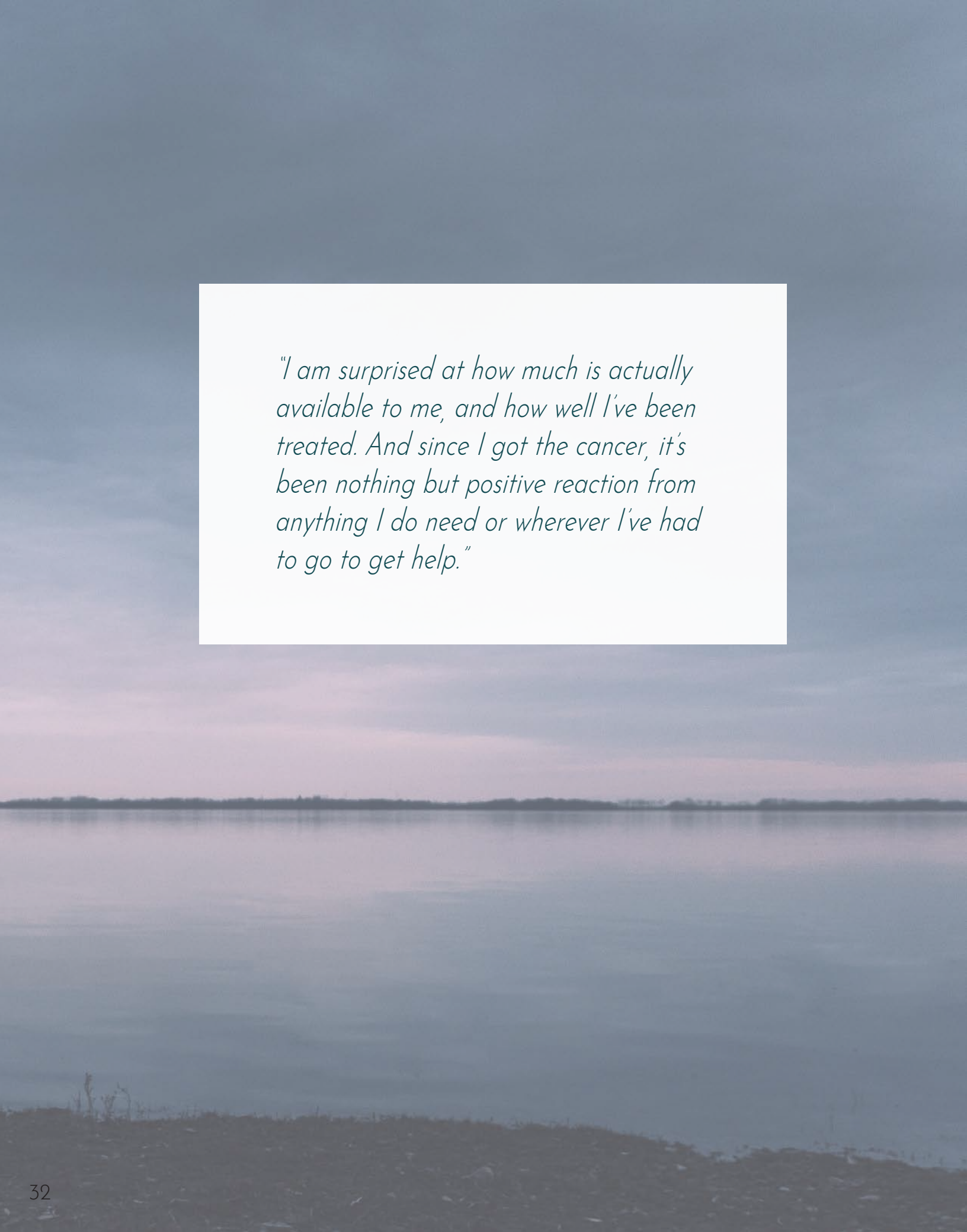
In the context of family estrangement, housing, health, and outreach workers, in many cases, became the primary support for the dying person. Linda was estranged from her biological family and considered the service providers of her local health non-profit organization as her family, what is called "chosen family." She describes what she said to them when she was first diagnosed with cancer:

I went up there one day [to the non-profit organization] and said, "Well you know, as far as I'm concerned… I do have family here, lots of family. I have nothing to do with them. Whatsoever. They didn't want anything to do with me. Fine. But I said, "Well, you guys, you don't get a choice in it. You're my family. So here it goes. I'm going to go for a hell of a ride and I need you to help me navigate."

Informal support networks (communities or individuals who looked out for the person), street-family, and occasionally biological family members, were present in the lives of many participants. The type of care they provided varied greatly. It ranged from intense 24/7 care (e.g., personal care, medical care, care coordination, pain and symptom management, psychosocial care) to providing support in the essentials of daily life, such as getting/buying food and medications, to estranged family members only making contact right before death and then providing support post-death, such as funeral arrangements.

Support people often had complex relationships with our vulnerable participants and had their own health issues. Their abilities to take on the informal, unpaid, caring role on which the palliative care system is built, was limited. They reported stress and burdens, including feeling trapped, a lack of freedom, and pressure to be present. It was tough to care for a dying person whose behaviours and/or lifestyles contradicted their care needs. They coped with challenging family dynamics, witnessed the care recipient in pain and not receiving enough support and finally dying. Other complications included their own financial stresses and housing issues, employment challenges, mental health and psychosocial stress, diseases and illnesses. Barriers also included whether health workers trusted them to administer medications; more distanced relationships; rules and policies of housing units; and travelling to care recipient or medical appointments. Chosen support people were often left out of the health-care interaction, communication, and decision-making for their loved ones before and after death. Engaging with support people emerged as a missing and necessary palliative care practice.

"The haves and the have nots become really amplified."



"I am surprised at how much is actually available to me, and how well I've been treated. And since I got the cancer, it's been nothing but positive reaction from anything I do need or wherever I've had to go to get help."

Justice at the end for some

In our study, when a person's case was assigned to a physician or nurse who had a palliative orientation and understood the social determinants of health, their end-of-life care improved.

By and large, when people received a "legitimate" (palliative) diagnosis and were assigned to service providers who had a palliative orientation, services came around them quickly and efficiently. People experienced good care in a way that they had never experienced through health and social services systems, including being believed; getting pain needs met; getting access to additional income and services; and being surrounded by care providers who were compassionate, kind and invested.

Cliff, who was a homeless Caucasian man and had a history of illicit drug use, faced several barriers to being diagnosed. When he developed back pain he sought help through community clinics. He was sent for X-rays at least twice that did not show any pathology and was told it was likely muscle pain. The pain increased and he used street drugs to deal with it but eventually was unable to work or afford drugs. When he went to the hospital emergency room, he refused to leave until he got some sort of help. He had lost a good deal of weight and was convinced there was something wrong. He was given an MRI and CT scan and diagnosed with advanced cancer in the spine. He was operated on immediately, given targeted radiation and told that he would not live more than six months. He was referred to hospice, which put the appropriate supports in place. Said Cliff:

> *I am surprised at how much is actually available to me, and how well I've been treated. And since I got the cancer, it's been nothing but positive reaction from anything I do need or wherever I've had to go to get help. They've been more than accommodating. I am getting top-rate service. They fast-tracked me through the system for any benefits that are available to me. So you know, I can't complain about anything right now. It's just anything I need is actually there for me. And it's been made quite clear that, just call if you need anything. I feel like I've been taken care of very well.*

A palliative designation resulted in people getting good care, sometimes for the first time in their lives. After a conversation with Lewis' case manager, one of our research assistants wrote:

> *[The case manager] said he's had a very hard life – he's a residential school survivor, to start with, and was homeless for many years, and now he finally has support and a good apartment, and he's dying. She talked about the injustice of that – of people only getting services when they're dying, after a lifetime of being underserved by the system and not having adequate access to resources that they need.*

This health manager echoes these sentiments:

> *I also think that it is a really sad comment that we would somehow privilege meeting or improving the quality of someone's social determinants of health at their end-of-life. It feels a bit like* ***too little, too late****. And I think for many of the people who I've experienced grief and loss over because they have died … many, many of them should not be dead.*


Loitering
Soliciting
Camping
Trespassing
Police Authorized to
Arrest and Enforce
Sections 4 and 10 of the
BC Trespass Act.

Recommendations

As a group of university researchers and health professionals we set out to make visible the issues related to access to care for people experiencing structural vulnerabilities who are also at the end-of-life. Our work would not have been possible without the guidance and advice of a group of health and social care professionals, who collectively called themselves Victoria's Palliative Outreach Resource Team or PORT. While it formed to promote quality end-of-life care, PORT exists now only as an acronym, as it has had no money to sustain its activities and its original physician, nurse and counsellor members, while involved, have moved on to other positions. Whatever occasional unpaid, off-hour work is done by current members depends on individual service providers' interests, willingness, and time to participate. While each agency supports the work of the remaining members of PORT, the provision of palliative approaches for marginalized populations does not squarely fit within any of their mandates. It is nobody's priority, with quality end-of-life care relying entirely on the good will of the community and the persistence of champions.

We present the main findings from our study within this context. Our recommendations are those that we hope will move us to ensuring equitable access to care for vulnerable populations at the end-of-life. As mentioned earlier, our work here awoke us to the realization that addressing this problem will not need huge amounts of money. Building the capacity of what we had in groups like PORT and expanding knowledge, training, and community capacity will go a long way to turn improvised palliative care into the reliable, sustainable norm.

In developing this study's list of recommendations, we are advocating for integrating a palliative approach to care[28, 29] for structurally vulnerable populations in our community. This means taking the important principles of palliative care (e.g., alleviation of symptoms, focus on quality of life, addressing what is most important for people facing serious illness and their chosen supporters, psychosocial, spiritual and peer support) and embedding them upstream into everyday care that happens in the community, wherever that happens to be. Our wish is to capitalize on the momentum brought about by this study, to engage the community in changing the ways in which care of the dying is delivered to the population. In the process we aim to enhance access to quality end-of-life care for people experiencing structural vulnerability and create the conditions for health and social service sectors, and the wider community, to work collaboratively to do so.

The conversations throughout the study on developing a new, comprehensive palliative approach prompted the questions that frame our recommendations. For example, service providers, often not medically trained or without access to medical records, wanted to know how to identify a person on a palliative trajectory (e.g., How do we teach people to notice signs of decline? How do we educate about the services available?). They wanted to know how to communicate with the person and their chosen family about their care plan, their goals of care, their worries, hopes, and fears. How could the plan of care reflect these issues and work across settings? How could they adapt palliative knowledge and skills? What knowledge and skill of caring for structurally vulnerable people needs to inform palliative care? As well, engaging chosen family and caregivers, including street family and front-line workers, is key in the development of a palliative approach. This includes asking people how they would design a palliative approach for themselves, friends, and family members.

With these sentiments in mind, we offer the following recommendations:

1 Address barriers in formal health care settings that prevent people experiencing structural vulnerabilities from receiving diagnosis, treatment, support, and care.

- Create educational opportunities for health care providers to learn about barriers to care for structurally vulnerable people and how they can best support them during their end-of-life experiences. This should include education based in principles of trauma and violence informed care, cultural safety, and harm reduction.
- Address policies (e.g., behavior policies, abstinence policies) that result in structurally vulnerable people avoiding, being turned away from, and leaving healthcare settings early without access to quality care, information, or follow-up.

2 Integrate palliative approaches to care where people experiencing structural vulnerability live and die.

- Promote knowledge sharing, coordination, and continuity between health care (e.g., acute care, palliative care, home and community care) and inner city services (e.g., housing, shelters, and health services) to address social determinants of health as a precursor to good palliative care.
- Support health care organizations to develop policy and strategies to mitigate risk and facilitate access to care in community settings (e.g., reviewing no-go building lists; housing worker or support people introduction/accompaniment; exploration of perceived versus real risk).
- Create accessible, non-medicalized education and resources for housing, health, and support workers working closely with structurally vulnerable people. This should include education on palliative approaches to care, supporting palliative health and social needs, navigating the palliative care system, and legal and financial resources available at end-of-life.
- Build on other Canadian models to develop mobile palliative care services with access to nurse and physician support for complex care needs, to coordinate, communicate with, build capacity, and educate people experiencing structural vulnerability, their support persons, and service providers involved in end-of-life care.
- Consider creating appropriate space in existing housing units for people to go when they need 24/7 support/health care but do not need to be in acute care.

3 Support non-traditional families (e.g., street family, inner city workers) and include them in decision-making processes and strategies.

- Address assumptions and policies in health care and housing organizations (e.g., privileging of biological family, guest policies) that prevent non-traditional family from caring for their loved ones at end-of-life.

- Accept and embrace that the classic divide between workers and clients is no longer the rule, as workers are in de facto family roles, coping with deep bereavement, and often in housing crisis and living in poverty themselves.

- Provide bereavement support for workers and support people to recognize and show respect for their important caregiving role. This may take forms beyond individual support to collective action against unjust and untimely deaths.

- Conduct further research exploring the roles of non-traditional families as caregivers in structurally vulnerable communities.

All these recommendations are doable. But education and tools alone will not create culture shift. Engagement and ongoing mentorship and coaching of staff, opportunities for dialogue and practice, and some resources are also necessary for good palliative care to come to vulnerable populations. We have already found promising models in Canada, the United States and the United Kingdom, where progress is happening without system overthrow or tax increases. These models vary widely, from individual case management approaches to palliative-bed designation to homeless hospices to surrogate homes.

We discovered quickly, however, that each model faces challenges to provide care for this diverse population. No one size fits all.

The only common denominator is community leadership. As social justice advocates, we – the researchers, support people, health professionals and clients in this study – are now armed with new knowledge and are ready to help lead change with others in our community beyond what we have accomplished in this three-year study.

Every dying person, no matter their social status or circumstances, deserves to die in dignity, in the presence of those who care about them, and without pain. Canada cannot continue to offer our palliative tools, training and tears to the most vulnerable citizens in our country only when it is too little, too late.

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