



Nurturing Partnerships. Reimagining Palliative Care

NURTURING OUR COLLECTIVE CAPACITY TO PROMOTE EQUITY-INFORMED PALLIATIVE CARE

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Piotr Burek
@burek75

I've said it before and I'll say it again, the amount of love and care I have for the humans in this group is beyond words.

Palliative care is about fighting injustice and caring for each other, and what incredible accomplices we have in doing so.

#ipac #yyj #justice #equity

Equity in Palliative Approaches to Care @access2care · Sep 17

Just finished our IPAC zine workshop facilitated by the always amazing @burek75
❤️ We are creating a zine about what palliative care in the inner city means for us. Stay tuned for the final product 📖





CANADIAN DEFINITION OF HOMELESSNESS

- Living outside or in places not fit for human habitation;
- Staying in temporary or emergency accommodations (e.g., emergency and transition shelters);
- Living in accommodations without security of tenure (e.g., 'couch surfing' or staying with friends or acquaintances); and
- Living at risk of homelessness due to financial insecurity or other factors (e.g., intimate partner violence, separation or divorce, etc.) that may compromise housing.

Gaetz, S.; Barr, C.; Friesen, A.; Harris, B.; Hill, C.; Kovacs-Burns, K.; Pauly, B.; Pearce, B.; Turner, A.; Marsolais, A. (2012) Canadian Definition of Homelessness. Toronto: Canadian Observatory on Homelessness Press.



235,000
Canadians experience
homelessness
EACH YEAR

How can health and social care



Ensure **equitable approaches to palliative care**, taking into account intersecting vulnerabilities?



Intervene early enough to promote **physical, emotional, social** and **spiritual** well-being so that people who are dying and their chosen family can live the best quality of life up until the time they die?

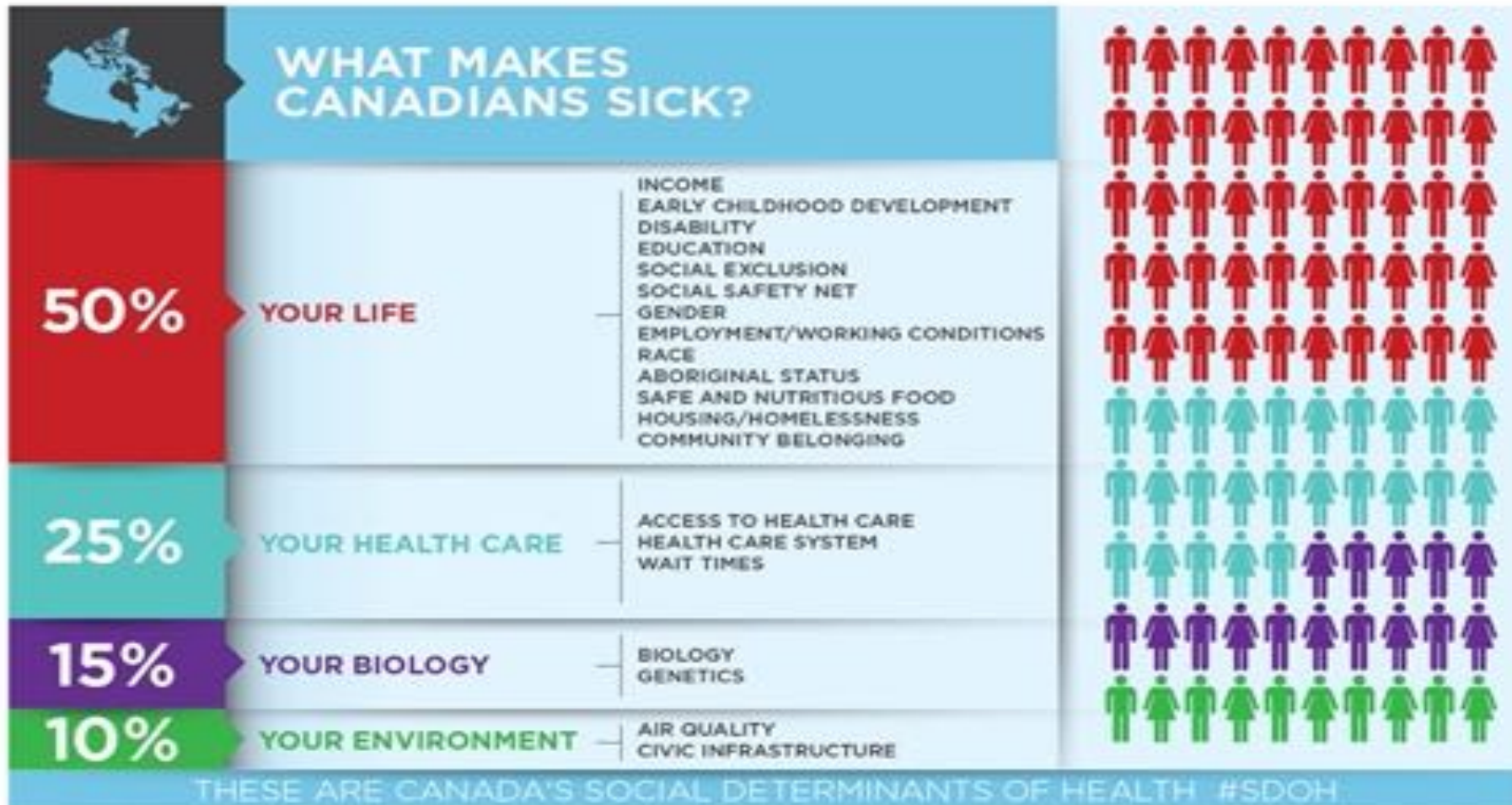


Prioritize **what matters most** as people are coming to the end of life?



Capitalize on the assets in our community and within our citizens to support equity-oriented palliative approaches to care and allow people to **live in the community** (if they wish) as they are dying?

WHY HEALTH EQUITY?



<https://www.homelesshub.ca/gallery/social-determinants-health-care>

WHY HEALTH EQUITY?

- Differences in the health of populations and mortality rates are largely due to social issues that are systemic, patterned, unjust and actionable, as opposed to random or caused by those who become ill.
- Health equity directs us to looking at how we can remove economic and social obstacles to health such as poverty and discrimination so that everyone has a fair and just opportunity to be healthy.

Whitehead, M. (1992). The concepts and principles of equity in health. *Health Promotion International*, 6(3), 217-228.

“Most definitions of palliative care ... do not make explicit the additional attention needed to address social and structural inequities that profoundly shape health, illness, and dying experiences for people who are made particularly vulnerable by a constellation of sociopolitical, economic, cultural, and historical forces.”

Reimer-Kirkham, Stajduhar, Pauly, et al. 2016

Death Is a Social Justice Issue Perspectives on Equity-Informed Palliative Care

**Sberyl Reimer-Kirkham, PhD, RN; Kelli Stajduhar, PhD, RN;
Bernie Pauly, PhD, RN; Melissa Giesbrecht, PhD; Ashley Mollison, MA;
Ryan McNeil, PhD; Bruce Wallace, PhD**

All too often, palliative care services are not responsive to the needs of those who are doubly vulnerable, being that they are both in need of palliative care services and experiencing deficits in the social determinants of health that result in complex, intersecting health and social concerns. In this article, we argue for a reorientation of palliative care to explicitly integrate the premises of health equity. We articulate the philosophical, theoretical, and empirical scaffolding required for equity-informed palliative care and draw on a current study to illustrate such an approach to the care of people who experience structural vulnerabilities.

Key words: discrimination, health equity, homelessness, marginalization, palliative care, poverty, public health, social justice, stigma, structural vulnerability

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MOST PEOPLE share a common desire to approach the end of life in a peaceful and dignified manner, in the presence of loved ones, and filled with feelings of safety,

Community Health Centre and PORT, Grey Shovel, Cool Aid Community Health Centre and PORT, Ashley Mollison, UVic; Taylor Tsui, UVic; Carolyn Shovel, UVic; and Kelley Roatelo, UVic). We thank our Advisory Group composed of member organizations of the Palliative Outreach Resource Team (PORT) in Victoria, British Columbia, Canada. We thank the presenters, panelists, facilitators, and generous contributors who made the PORT in the Storm workshop possible, including The Sovereign Order of St. John of Jerusalem Knights Hospitalier Victoria Commandery, Victoria Hospice, PORT, BC Centre for Excellence in HIV/AIDS, Palliative Education and Care for the Homeless (PEACH), AIDS Vancouver Island, Victoria Cool Aid Society, the Initiative for a Palliative Approach in Nursing, Evidence and Leadership (iPanel), www.ipanel.ca, and the UVic Institute on Aging and Lifelong Health.

The authors have disclosed that they have no significant relationships with, or financial interest in, any commercial companies pertaining to this article.

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DOI: 10.1097/ANS.0000000000000146

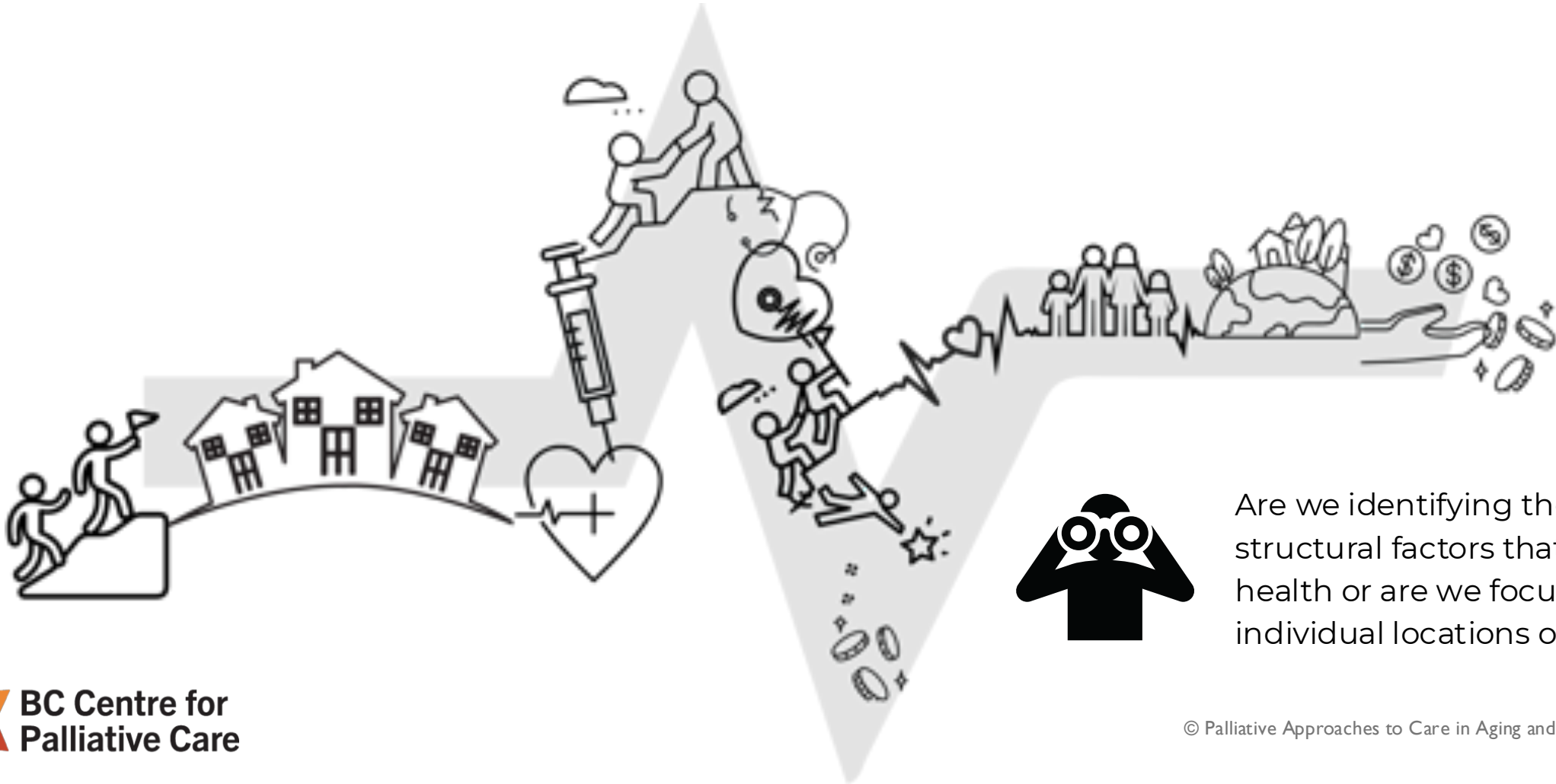
EQUITY-ORIENTED PALLIATIVE CARE

Gives us a lens to look at who current palliative care programs are working for and serving, and who they are not

- Who are our current programs designed to serve?
- Do our palliative care programs pay explicit attention to equity and how?
- Are we directing our resources to those with the greatest need?



SOCIAL AND STRUCTURAL DETERMINANTS OF HEALTH



“

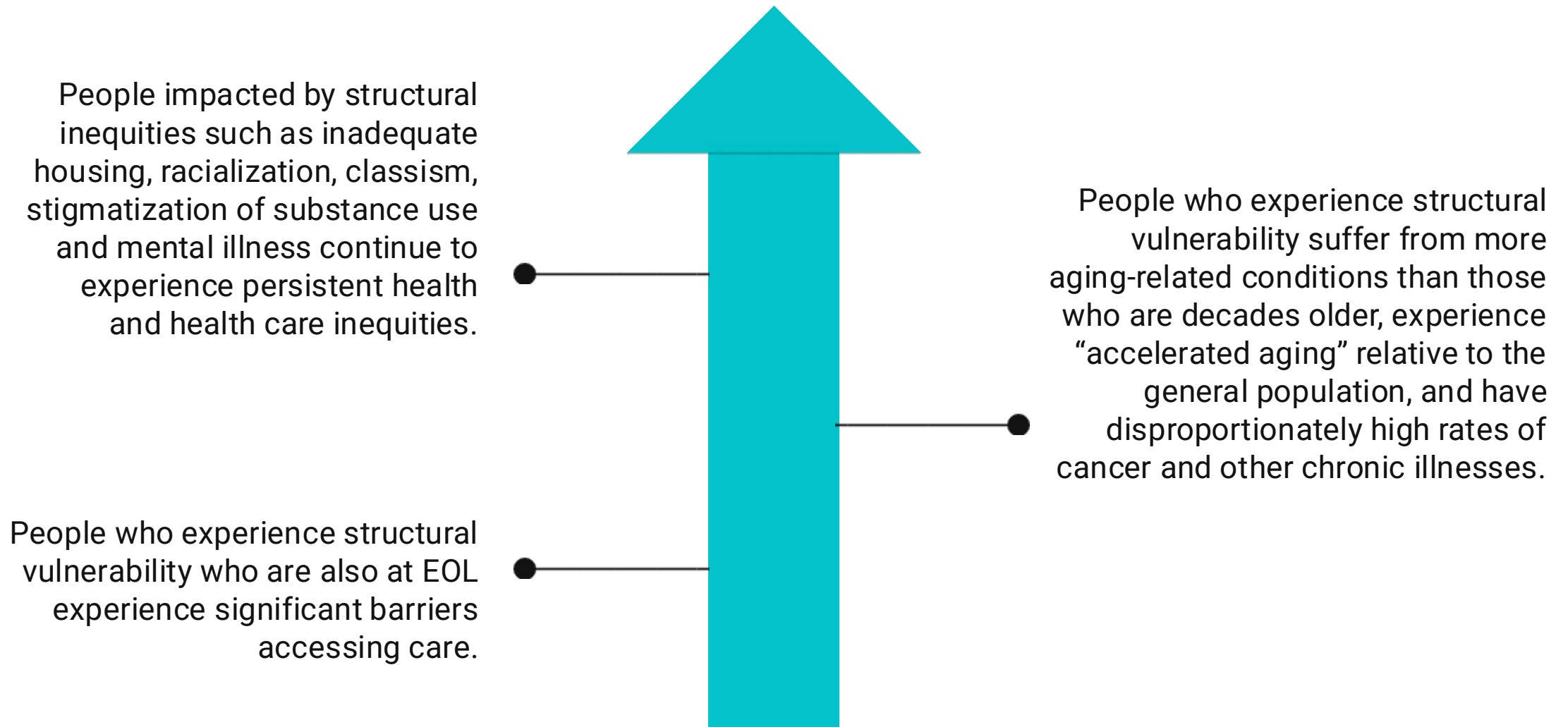
POWERLESSNESS IS MAKING US SICK.

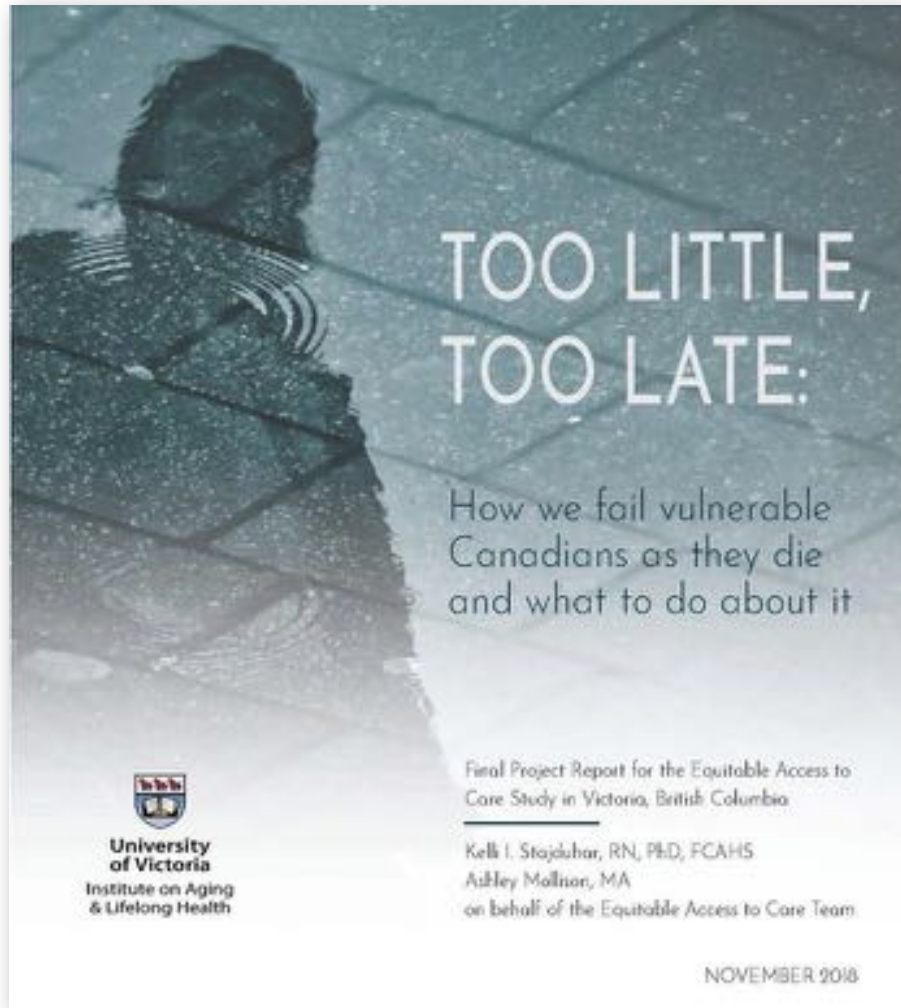
- Anthony Iton, Unnatural Cause

Sustained imbalance in power can become reinforced in systems and structures that affect decision making and resource allocation.

Those who lack power experience persistent and avoidable inequities in opportunity and health.

Palliative approaches to care for people experiencing structural vulnerabilities





<https://palliativeapproaches.uvic.ca/reports/>



- “We don’t see many of ‘these’ people.”
- Our palliative care services are not designed for populations of people facing inequities
- People’s focus is on survival and immediate needs; palliative care not really on the radar
- Big silos in care in which people fall in between – social services, health services, mental health services, etc.

Stajduhar, K. I., Mollison, A., Giesbrecht, M., McNeil, R., Pauly, B., Reimer-Kirkham, S., Dosani, N., Wallace, B., Showler, G., Meagher, C., Krakic, K., Gleave, D., Teal, T., Rose, C., Showler, C. & Rounds, K. (2019). “Just too busy living in the moment and surviving”: barriers to accessing health care for structurally vulnerable populations at end-of-life. *BMC Palliative Care*, 18(1). <https://doi.org/10.1186/s12904-019-0396-7>













Health & Place

Volume 53, September 2018, Pages 43-51



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

Melissa Giesbrecht^a  , Kelli I. Stajduhar^{a b} , Ashley Mollison^a , Bernie Pauly^{b c} ,
Sheryl Reimer-Kirkham^d , Ryan McNeil^{e f} , Bruce Wallace^g , Naheed Dosani^h ,
Caelin Rose^a 

Health care services, including
palliative care, do not feel safe
or welcoming for people and
their chosen supporters.

Giesbrecht, M., Stajduhar, K. I., Mollison, A., Pauly, B., Reimer-Kirkham, S., McNeil, R., Wallace, B., Dosani, N. & Rose, C. (2018). Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life. *Health & Place*, 53, 43–51. <https://doi.org/10.1016/j.healthplace.2018.06.005>



“Everybody in this community is at risk of dying”: An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner-city settings

Published online by Cambridge University Press: 07 May 2020

- Identification of people who could benefit from a palliative approach to care is complex
- Lack of knowledge and awareness of palliative approaches to care among community workers and tools to support them in the community
- Questions related to who is eligible for palliative care services when everybody in the community is at risk of dying

Stajduhar, K. I., Giesbrecht, M., Mollison, A. & d'Archangelo, M. (2020). “Everybody in this community is at risk of dying”: An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner-city settings. *Palliative and Supportive Care*, 1–6. <https://doi.org/10.1017/s1478951520000280>


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Original Article



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

Kelli I Stajduhar ^{1,2}, Melissa Giesbrecht¹, Ashley Mollison¹, Naheed Dosani³, and Ryan McNeil^{4,5}

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

Caregiving in the context of inequities is fundamentally different than what we would consider in mainstream palliative care where we have ‘family’ caregivers who heavily support our work.

Stajduhar, K. I., Giesbrecht, M., Mollison, A., Dosani, N. & McNeil, R. (2020). Caregiving at the margins: An ethnographic exploration of family caregivers experiences providing care for structurally vulnerable populations at the end-of-life. *Palliative Medicine*, 34(7), 946–953. <https://doi.org/10.1177/0269216320917875>

Original Article



***“Once you open that door, it’s a floodgate”:
Exploring work-related grief among community
service workers providing care for structurally
vulnerable populations at the end of life through
participatory action research***

Melissa Giesbrecht¹ , Ashley Mollison¹, Kara Whitlock¹
and Kelli I Stajduhar^{1,2} 

Palliative Medicine

1–9

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Grief experienced by community service workers (de facto family) is unrecognized, invisible, and profound.

Giesbrecht, M., Mollison, A., Whitlock, K. & Stajduhar, K. I. (2022). “Once you open that door, it’s a floodgate ”: Exploring work-related grief among community service workers providing care for structurally vulnerable populations at the end of life through participatory action research. Palliative Medicine, 026921632211397. <https://doi.org/10.1177/02692163221139727>

Original Research



‘The beauty and the less beautiful’: exploring the meanings of dying at ‘home’ among community and practitioner representatives and advocates across Canada

Laura Funk ¹, Marian Krawczyk ², Maria Cherba³, S. Robin Cohen ⁴, Carren Dujela⁵, Camille Nichols⁶, and Kelli Stajduhar⁷

Background: Significant structural and normative pressures privilege the ideal of dying at home in Canada. At the same time, the social complexities and meanings associated with dying in particular locations remain critically unexamined.

Objective: The aim of this study is to explore how diverse community members, including health and social care stakeholders, talk about preferences for locations of dying, with a particular focus on meanings of dying at home.

PALLIATIVE
APPROACHES



<https://palliativeapproachesuvic.ca>

NEW RESEARCH
NEW RESEARCH

BMC PALLIATIVE CARE

JANUARY 2024

“YOU CAN’T DIE HERE”:

An exploration of the barriers to
dying-in-place for structurally
vulnerable populations

KELLI I. STAJDUHAR, MELISSA GIESBRECHT, ASHLEY MOLLISON, KARA WHITLOCK,
PIOTR BUREK, FRASER BLACK, JILL GERKE, NAHEED DOSANI, SIMON COLGAN



University
of Victoria

Institute on Aging and Lifelong Health,
Nursing



University
of Victoria

Institute on Aging and Lifelong Health,
Nursing



Equity in Palliative Approaches to Care (ePAC) is a community collaborative informed by a research program led out of the University of Victoria. Members of the collaborative work together to conduct research with local, national and international partners, and develop resources and tools, programs, and services aimed at improving access to quality care for people facing the end-of-life and who also face inequities like homelessness, poverty, isolation, racism, and stigma.





Pan-Canadian Research Collaborative

PCOAT
Palliative
Care
Outreach and
Advocacy
Team
(Edmonton, AB)



PEACH
Palliative
Education
and Care for
the Homeless
(Toronto, ON)



PORT
Palliative
Outreach
Resource
Team
(Victoria, BC)




CAMPP
Community
Allied Mobile
Palliative
Partnership
(Calgary, AB)



PACT
Palliative
Advocacy &
Care Team
(Thunder Bay,
ON)





01. Address barriers in formal health care settings that prevent people from receiving diagnosis, treatment, support, and care.

Palliative Outreach Resource Team (PORT)



My Advance Care Plan: ACP Tool

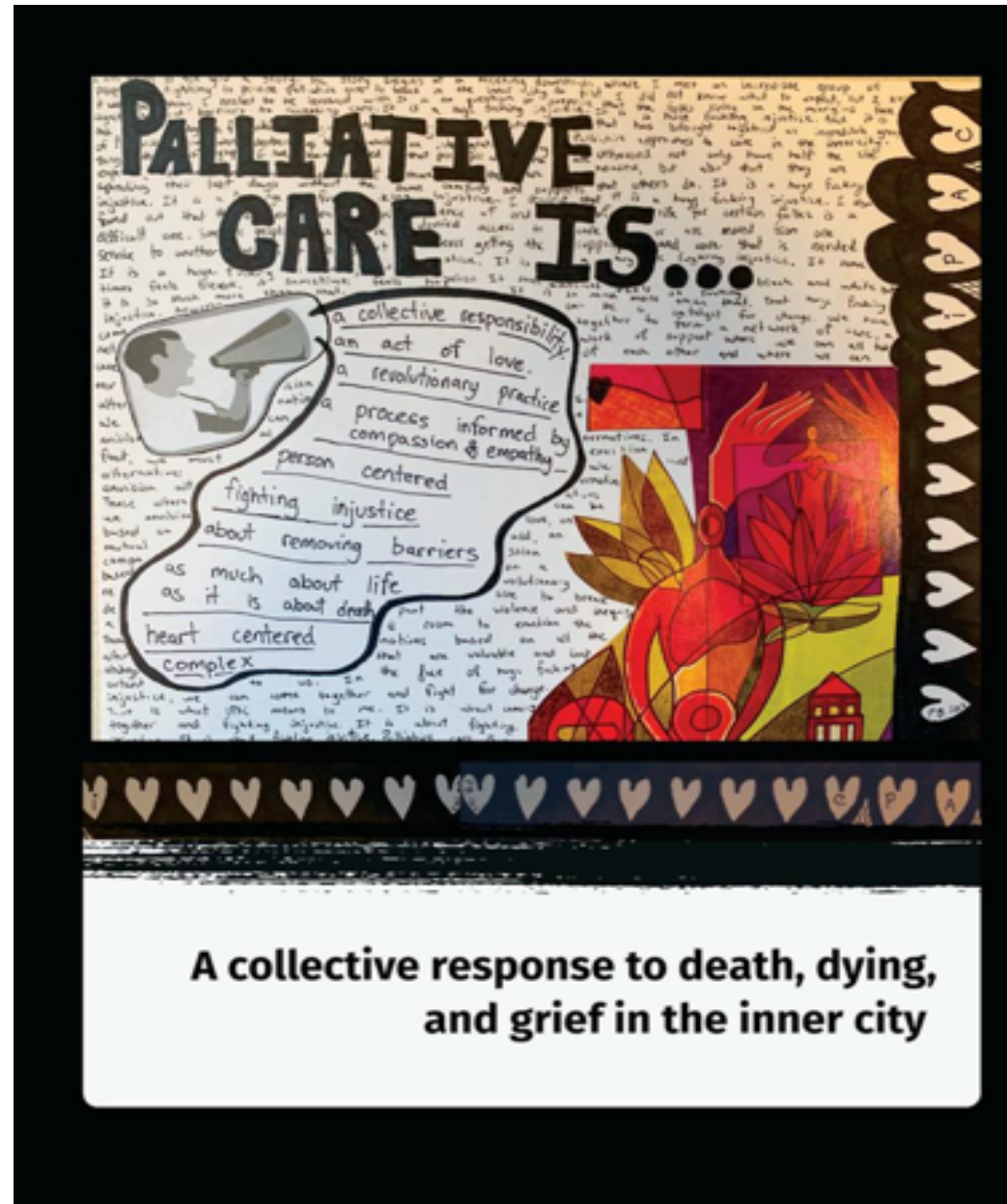


02. Integrate palliative approaches to care where people experiencing structural vulnerability live and die.

Adapted palliative care tools and resources

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

Inner-City Action Team





Improving Equity in Access to Palliative Care

A Pan-Canadian Collaborative

“

History teaches us that all sustainable change happens at the grassroots level and then spreads out from there to create further ripples of change.

Some of these ripples combine to create big waves; most trigger countless small and unexpected impacts that overlap and intersect in ways we'll never know the full importance of.

Cormac Russell and John McKnight

The Connected Community: Discovering the Health, Wealth, and Power of Neighborhoods



Stajduhar, K. & Gott, M. (2023). Closing the health equity gap in palliative care: The time for action is now. *Palliative Medicine*, 37(4), 424–425. <https://doi.org/10.1177/02692163231164729>

Final Reflections

- Historically, hospice and palliative care mostly originated outside the health care establishment
- Palliative care has now (for the most part) become part of the mainstream of health care provision, an exemplar of best practice in care of the dying, and now, an important player in policy making
- Entry into the 'mainstream' has been significant, but not without problems and perhaps some unanticipated consequences

Final Reflections

- Over reliance on ‘specialty models’ – “specialized palliative care is not the main way we should deal with dying but it’s an important part”
- Creep of the biomedical model – enhanced emphasis on better “pain and symptom management” perhaps at the expense of other important concerns
- Professionalization of the workforce and some diminishment of social models of volunteerism
- Community ownership and conceptualizations of death and dying – once considered a civic and social responsibility has given way to all the trappings of institutionalized, professionalized, medicalized and “other-ized” systems of care
- De-capacitating community to contribute to caring for their own



To what extent do these developments compromise the early ideals of Hospice Palliative Care?

To what extent have these developments given rise to inequities in palliative care?

Final Reflections

- Somewhat
- We do not want to lose what we have gained –mainstreaming of palliative care “hard won”
- Learn from our history
- Move forward in thoughtful ways
- Rethink of future directions:
 - Renewal of emphasis on the social aspects of dying
 - engaging our communities in what is important to them
 - Consider the social determinants of health as THE critical intervention in the context of caring for people who face inequities.



**Palliative care has much to offer, but we must attend to equity issues.
And ‘how’ we do equity work is probably more important than ‘what’ we do.**

Contact Us!

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