CHCA Project ECHO Home-Based Palliative Care

All Teach, All Learn

Bridging the Knowledge Gap in Home-Based Palliative Care







Unpacking the Principles of a Palliative Approach to Care:

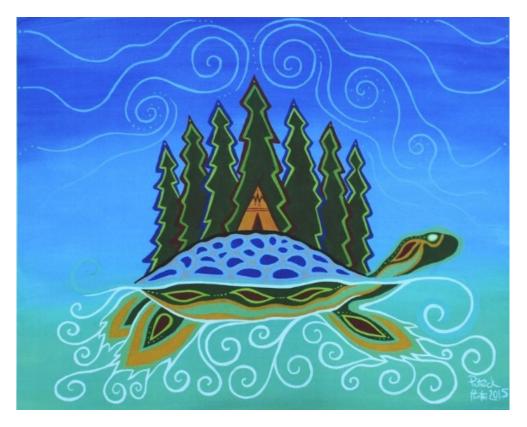
Addressing Barriers to Care

Teaching Presentation: Kelli I. Stajduhar, PhD, RN, FRSC, FCAHS, FCAN University of Victoria, Canada, 2023/2024 Hood Fellow, University of Auckland

Case Study: Kate Leahy, BSN, NP (student), Founding Nurse Coordinator for the Palliative Outreach Resource Team (PORT), Victoria, BC

Host: Jennifer Campagnolo, Canadian Home Care Association November 13, 2024

Land Acknowledgement



Artist Credit: Patrick Hunter

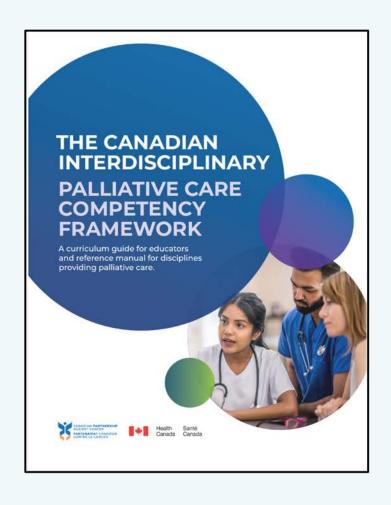
We recognize with humility and gratitude that Canada is located in the traditional, historical and ceded and unceded Lands of First Nation, Inuit and Metis

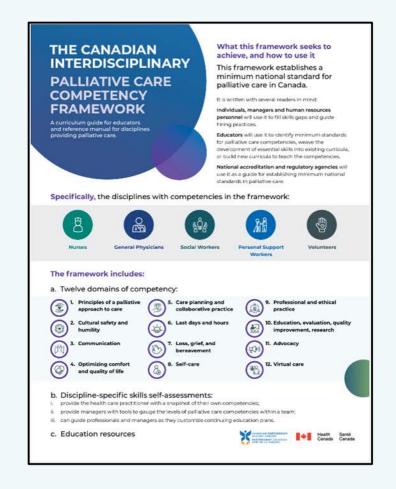
Peoples. On behalf of us all, we acknowledge and pay respect to the Indigenous peoples past, present and future who continue to work, educate and contribute to the strength of this country.

Reminders

- Say "Hello!" and introduce yourself via the chat! Remember to select "Everyone".
- Use the chat function if you have any comments or are having technical difficulties.
- Captioning is available and can be activated through your Zoom options.
- Microphones are muted. **Please use the Q&A function to ask the panelists questions.** We will be taking time to answer any questions at the end of the presentation.
- This session is being recorded and will be available at https://cdnhomecare.ca/chca-project-echo-home-based-palliative-care
- Remember not to disclose any Personal Health Information (PHI) during the session.

THE CANADIAN INTERDISCIPLINARY PALLIATIVE CARE COMPETENCY FRAMEWORK





Unpacking the Principles of a Palliative Approach to Care



Domain 1: Principles of a palliative approach to care

Palliative care aims to improve the quality of life of people with life-limiting conditions and their designated families or caregivers. This person-centred care ideally begins at diagnosis, continues into bereavement, and is for people of any age.¹



Unpacking the Principles of a Palliative Approach to Care



Addressing barriers to care¹

For members of the Interdisciplinary Team (nurses, SW, PSWs, generalist physicians and volunteers) competency is a combination of the SKILLS, KNOWLEDGE and ATTITUDES needed to:

- Identify and understand barriers, and how they affect access and care, with particular attention to members of underserviced populations.
- Address barriers (including misperceptions, beliefs, and attitudes towards palliative care) affecting the person, designated family or caregiver(s), and colleagues, that undermine access to high-quality palliative care.



Introductions



Kelli I. Stajduhar, PhD, RN, FRSC, FCAHS, FCAN
Professor and Canada Research Chair
Palliative Approaches to Care in Aging & Community
Health, School of Nursing, University of Victoria, Canada
2023/2024 Hood Fellow, University of Auckland



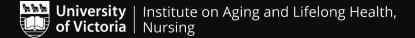
Kate Leahy, BSN, NP (student)
Founding Nurse Coordinator for the Palliative
Outreach Resource Team (PORT), Victoria, BC



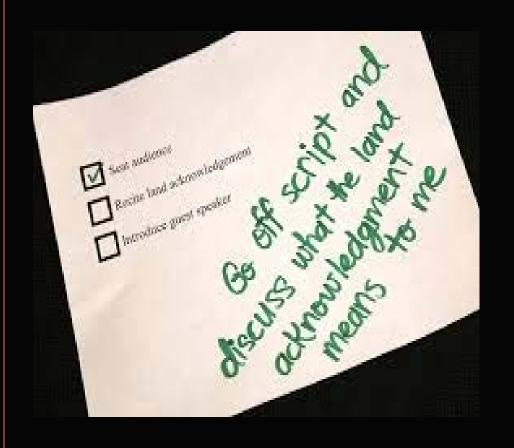
Unpacking the Principles of a Palliative Approach to Care: Addressing Barriers to Care

Kelli I. Stajduhar, PhD, RN, FRSC, FCAHS, FCAN
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Kate Leahy, BSN, NP (student)
Founding Nurse Coordinator for the Palliative Outreach Resource Team (PORT), Victoria, BC



Territorial Acknowledgement



Why does a palliative approach to care matter in contexts of inequity?

What do we mean when we say equity-oriented palliative care?

What kinds of adaptations (based on research) in thinking do we need to integrate equity-oriented palliative care?

Case study

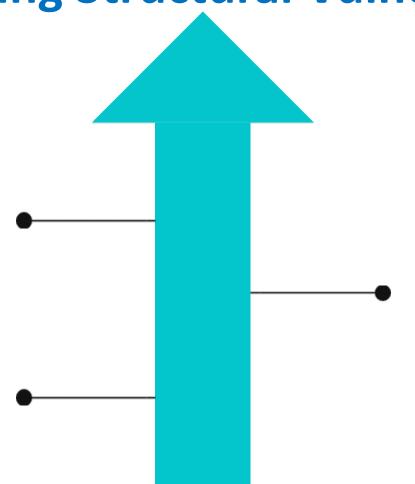
Resources, conclusions and questions



Palliative Approaches to Care for People Experiencing Structural Vulnerabilities

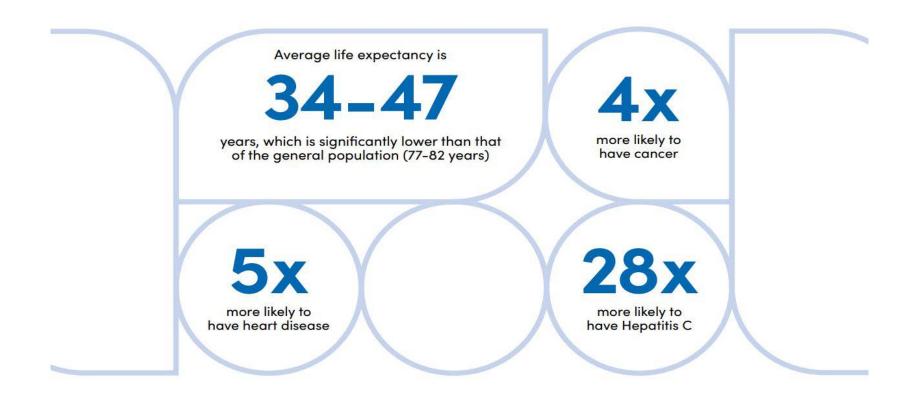
People impacted by structural inequities such as inadequate housing, racialization, classism, stigmatization of substance use and mental illness continue to experience persistent health and health care inequities.

People who experience structural vulnerability who are also at EOL experience significant barriers accessing care.

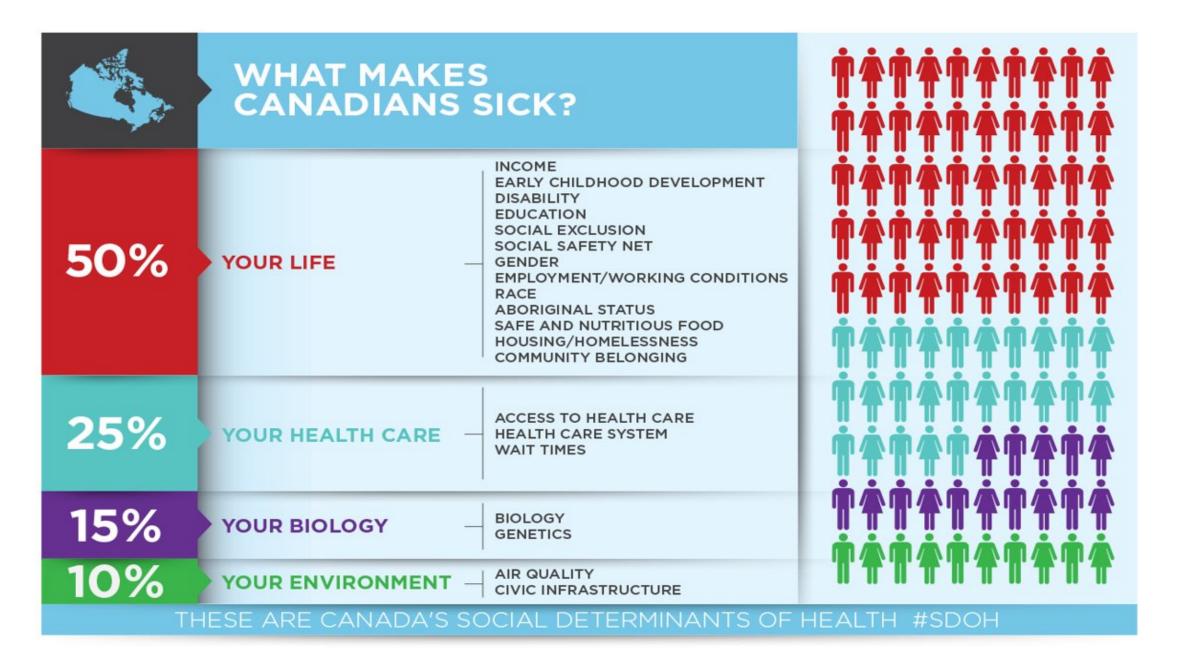


People who experience structural vulnerability suffer from more aging-related conditions than those who are decades older, experience "accelerated aging" relative to the general population, and have disproportionately high rates of cancer and other chronic illnesses.

Homeless Health in Canada



St Michael's Hospital, 2014; Podymow et al, 2006; Cagle, 2009; Plunkett, 2016





Social Determinants of Health

Digging at the roots, not just low hanging fruit:

The reproduction of the social determinants of health when the structural determinants are left untouched

~ Dr Nanky Rai, 2017

Structural Disadvantage

Structural vulnerabilities

Structural vulnerabilities: i.e. homelessness, poverty, criminalization, racism, and stigma

Chronic illness

Chronic illness: i.e. lung, liver, or kidney disease, cancer, HIV/AIDS

Severe disadvantage when health declines

"It's a time ... at the end of your life when I think it brings into view the things that are there and the things that aren't.

The haves and the have nots become really amplified."

- Inner City Nurse

Advances in Nursing Science Vol. 39, No. 4, pp. 293-397 Copyright © 2016 Wolten Kluwer Health, Inc. All rights reserved.

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

Sberyl Reimer-Kirkbam, PbD, RN; Kelli Stajdubar, PbD, RN; Bernie Pauly, PbD, RN; Melissa Giesbrecht, PbD; Asbley Mollison, MA; Ryan McNeil, PbD; Bruce Wallace, PbD

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, powerty, public health, social justice, stigma, structural vulnerability

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Lifelong Health (Ms. Mollions), and School of Social
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Wallace), University of Victoria, Carnala; and
British Columbia Centre for Excellence in HPV/AIDS
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Columbia, Canada (Dr. McNeil).

This article originates with the Equitable Access to Care for People With Life Limiting Conditions Study team led by Dr Kelli Stajdubar (principal investigator) and is supported by a grant from the Canadian Institutes of Health Research (MOP 133578). The authors are also members of carious research initiatives that inform their contributions to this paper, including the Equity Lens in Public Health Project that is funded by Canadian Institutes of Health Research. We are grateful to the participants of the Equitable Access to Care for People with Life Limiting Conditions Study and the research team (Kelli Stajdubar, University of Victoria (UVic); Ryan McNeil, BC Centre for Excellence in HIV/AIDS; Bernadette Pauly, UVic; Bruce Wallace, UVic; Sheryl Reimer-Kirkbam, Trinity Western University; Nabood Dosani, Inner City Health Associates and McMaster University; Caelin Rose, Victoria Hospice; Danica Gleave, Cool Aid Community Health Centre and Palliative Outreach Resource Team (PORT): Kristen Kvaleic, AIDS Vancouver Island and PORT; Caite Meagher, Cool Aid M OST 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 Showler, Cool Aid Community Health Centre and PORT; Ashley Mollison, UVic; Taylor Teal, UVic; Carolyn Showler, UVic and Kelsey Rounds, 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 Hospitaller 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.

Correspondence: Sheryl Reimer-Kirkham, PhD, RN, School of Nursing, Trinity Western University, Langley, BC V2Y IYI, Canada (Sheryl Kirkham@tten.ca).

DOI: 10.1097/ANS.0000000000000146

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"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







Equity-Oriented Palliative Care

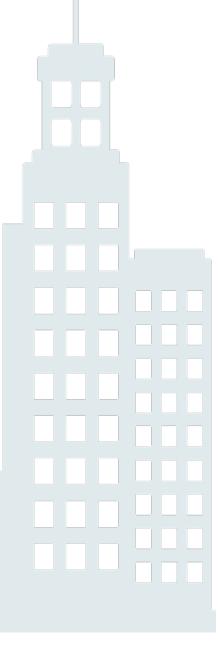
- Gives us a lens to look at who current palliative care programs and working for and serving, and who they are not
- Who are our palliative care programs designed to serve?
- Do our palliative care programs pay explicit attention to equity?
- Are we directing our resources to those with the greatest need?

Systemic and Social Inequities



Stajduhar, K., Mollison, A., Giesbrecht, M., et al. 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(11), https://doi.org/10.1186/s12904-019-0396-7.

Stajduhar, K.I., Giesbrecht, M., Mollison, A., & d'Archangelo, M. (2020 . Just too busy living in the moment and surviving: Barriers to accessing health care for structurally vulnerable populations at end-of-life: An ethnographic exploration on the potential of integrating a palliative approach to care among workers in inner city settings. Palliative & Supportive Care, 18(6), 670-675.





Closing the health equity gap in palliative care: The time for action is now

Palliative Medicine
2023, Vol. 37(4) 424–425
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DOI: 10.1177/02692163231164729
journals.sagepub.com/home/pmj

\$SAGE

Kelli Stajduhar¹ and Merryn Gott²

In order to "leave no one behind," the Worldwide Hospice Palliative Care Alliance's 2021 campaign called for governments and policymakers to prioritize equity-focused palliative care and to tackle structural inequities in end-of-life experience and bereavement. The campaign was reflective of a broader shift to address health equity driven by the recognition that, despite decades of research and health interventions, vast disparities exist in health outcomes and health care experiences both between, and within, countries. In her widely cited paper on equity in health, Whitehead¹ explains that health inequities are avoidable and potentially remedial differences in health

palliative care services, responds to the needs of the dying.

The collection of papers in this special issue of *Palliative Medicine* highlights recent evidence and practices, as well as the potential of research methodologies under-used within palliative care. It also points to some of the thorny issues that the field of palliative care faces in its efforts to close the health equity gap and the hard work required to get there. Indeed, the field of equity-focused palliative care is in its infancy. Modern day palliative care was developed to improve the quality of dying for those with cancer, with greater attention paid in recent years to others

Equity in palliative care means paying attention to power and working to address the social and structural determinants of health.

In this sense, addressing the social and structural determinants of health is a first-line palliative care intervention in contexts of inequity.

Over a Decade of Evidence...

Stajduhar et al. BMC Palliative Care (2019) 18:1 https://doi.org/10.1186/s12904-019-0396-7

BMC Palliative Care

RESEARCH ARTICLE

Open Access

"Just too busy living in the moment and surviving": barriers to accessing health care for structurally vulnerable populations at end-of-life

K. I. Stajduhar^{1,4*}, A. Mollison¹, M. Giesbrecht¹, R. McNeil^{2,3}, B. Pauly^{4,5}, S. Reimer-Kirkham⁶, N. Dosani⁷, B. Wallace⁸, G. Showler⁹, C. Meagher⁹, K. Kvakic¹⁰, D. Gleave⁹, T. Teal¹⁰, C. Rose¹, C. Showler¹ and K. Rounds¹

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

https://pubmed.ncbi.nlm.nih.gov/30684959/



Health & Place

Volume 53, September 2018, Pages 43-51





Supportive

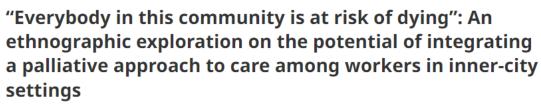
Hospitals, clinics, and palliative care units: Place-based experiences of formal healthcare settings by people experiencing structural vulnerability at the end-of-life

```
Melissa Giesbrecht <sup>a</sup> △ ⋈, Kelli I. Stajduhar <sup>a b</sup> ⋈, Ashley Mollison <sup>a</sup> ⋈, Bernie Pauly <sup>b c</sup> ⋈, Sheryl Reimer-Kirkham <sup>d</sup> ⋈, Ryan McNeil <sup>e f</sup> ⋈, Bruce Wallace <sup>g</sup> ⋈, Naheed Dosani <sup>h</sup> ⋈, Caelin Rose <sup>a</sup> ⋈
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Show more V

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

https://pubmed.ncbi.nlm.nih.gov/30055467/



Published online by Cambridge University Press: 07 May 2020

Kelli I. Stajduhar, Melissa Giesbrecht D, Ashley Mollison and Margo d'Archangelo

Show author details >

Article

Metrics

Identification of people who could benefit from a palliative approach to care is complex

Questions related to who is eligible for palliative care services when everybody in the community is at risk of dying

Lack of knowledge and awareness of palliative approaches to care among community workers and tools to support them in the community

https://pubmed.ncbi.nlm.nih.gov/32378499/



Association between opioid use disorder and palliative care: a cohort study using linked health administrative data in Ontario, Canada

Jenny Lau MD MSc, Mary M. Scott MSc, Karl Everett MSc, Tara Gomes PhD, Peter Tanuseputro MD MHSc, Sheila Jennings LLB PhD, Rebecca Bagnarol MPH, Camilla Zimmermann MD PhD, Sarina R. Isenberg PhD

Cite as: CMAJ 2024 April 29;196:E547-57. doi: 10.1503/cmaj.231419

https://www.cmaj.ca/content/196/16/E547



Opioid safety recommendations in adult palliative medicine: a North American Delphi expert consensus

Jenny Lau ⁽¹⁾, ^{1,2} Paolo Mazzotta, ^{2,3} Ciara Whelan, ^{2,3} Mohamed Abdelaal, ^{1,4} Hance Clarke ⁽¹⁾, ^{5,6} Andrea D Furlan, ^{7,8,9,10} Andrew Smith, ^{10,11,12} Amna Husain, ^{2,3} Robin Fainsinger, ¹³ David Hui, ¹⁴ Nadiya Sunderii, ^{15,16} Camilla Zimmermann ⁽¹⁾, ^{14,17}

➤ Additional supplemental material is published online only. To view, please visit the journal online (http://dx.doi. org/10.1136/bmjspcare-2021-003178).

For numbered affiliations see end of article.

ABSTRACT

Objectives Despite the escalating public health emergency related to opioid-related deaths in Canada and the USA, opioids are essential for palliative care (PC) symptom management. Opioid safety is the prevention, identification and management of opioid-related harms. The Dalphi technique was used to develop expert.

Key messages

What was already known?

- The opioid crisis has had an effect on all aspects of society, particularly in the USA and Canada.
- Guidelines on management of opioid safety have focused on chronic non-cancer.

https://pubmed.ncbi.nlm.nih.gov/34389553/

Palliative Medicine

Volume 34, Issue 7, July 2020, Pages 946-953 © The Author(s) 2020, Article Reuse Guidelines https://doi.org/10.1177/0269216320917875



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 (D) 1,2, Melissa Giesbrecht 1, Ashley Mollison 1, Naheed Dosani 3, 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

https://pubmed.ncbi.nlm.nih.gov/32340556/

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

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DOI: 10.1177/0269216322113972

SSAGE

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

Abstract

Background: At the end of life, people experiencing structural vulnerability (e.g. homelessness, poverty, stigmatization) rely on community service workers to fill gaps in access to traditional palliative services. Although high levels of burnout are reported, little

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

https://pubmed.ncbi.nlm.nih.gov/36461158/

Meet Henry



Henry's Social Context



Common Demographics



- older young
- un-housed or unstably housed
- high burden of chronic disease
- complex prognostication
- substance use common but not the rule
- varied supports systems

(Stadjuhar et al., 2019; Moore et al., 2024; Van Dogen et al., 2020)

Henry's Illness Journey

Metastatic lung cancer Admitted for pain control Discharged with PORT following Worsening symptom burden; home oxygen



Transitioned to a local emergency shelter

Collaboration with housing & CHS

Developed a spinal cord compression

Transferred to hospice for EOL care

Challenges & Barriers

Everybody in this community is at risk of dying" - Outreach Worker

- case identification
- advanced disease presentation
- traditionally defined palliative trajectories
- traumatic encounters with health & social services
- competing interests
- logistics
- perceived risk

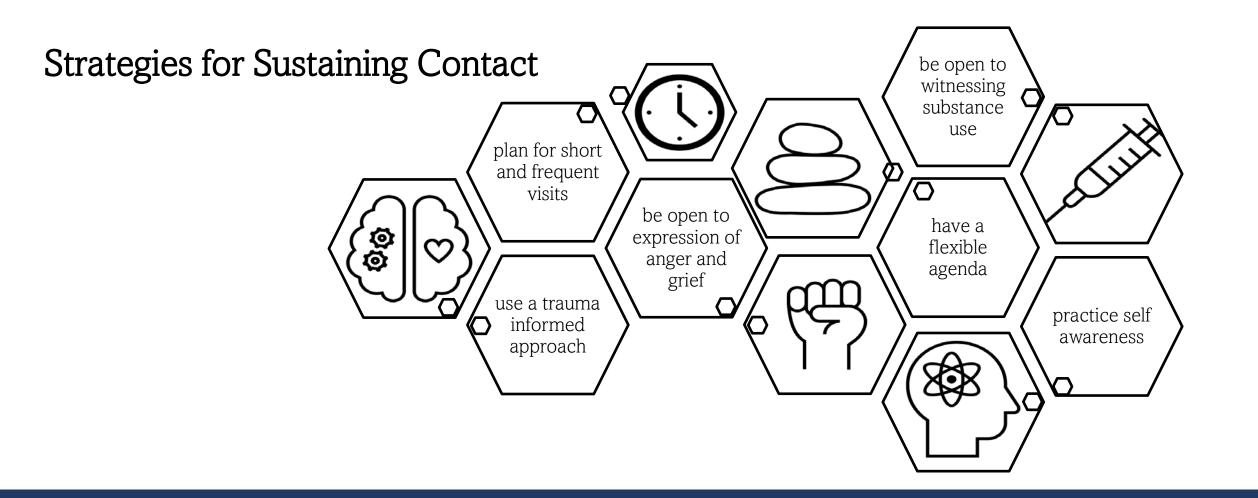


(Stajduhar et al., 2019; Moore et al., 2024; Van Dogen et al., 2020)

Strategies for Making Contact



- adopt a low barrier referral process
- gather intel from multiple sources
- meet the person where they're at– literally & figuratively

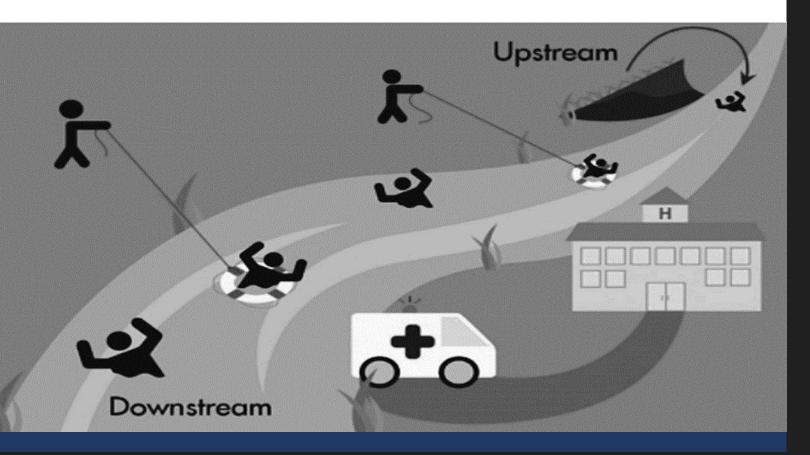


Navigating Care Provision & GOC Conversations



- recognize & address SDOH/basic needs early
- anticipate potential substance use & normalize it
- identify & collaborate with involved teams
- adjuvant pain management & frequent reassessment of prescribed medication
- daily dispense
- take home naloxone
- TSDM identification
- MOST conversations

Care Transitions



www.equityinpalliativecare.com

"...in the final three months before death 77% of the patients were transferred at least once to another setting and 45% of the patients had three or more such transitions."

(Van Dongen, et al., 2020)

Strategies to Successfully Navigate Transitions

- prep the receiving team
- stay involved for continuity & support
- communicate with outpatient teams
- prepare for unplanned discharges
- develop collaborative care plans to support substance use



Take Home Points

- systems are not independent of people working within them
- adopt curiosity & kindness
- discomfort is normal...it probably means you're doing it right ©
- be creative
- change takes time





Inequities affect all people but they have especially strong impacts upon the health of those living in poverty. Adding social sciences evidence – the understanding of social structures and of power relationships – we have now accumulated indisputable evidence that "social injustice is killing people on a grand scale."



LEAVE NO ONE BEHIND

EQUITY IN ACCESS TO PALLIATIVE CARE

World Hospice & Palliative Care Day

,,,

Zaman, M., Espinal-Arango, A., Mohapatra, S., & Jadad, A. (2021). What would it take to die well? A systematic review of systematic reviews on the conditions for a good death. *The Lancet Health Longevity*, 2(9), e593-e600.

dying at the preferred place

relief from pain and psychological distress

emotional support from loved ones

autonomous treatment decision making

avoidance of futile life-prolonging interventions and of being a burden to others

right to assisted suicide or euthanasia

effective communication with professionals

performance of rituals



Image from Irish Hospice Foundation: https://hospicefoundation.ie/wp-content/uploads/2023/09/Dying-Well-at-Home-Report-Irish-Hospice-Foundation.pdf

What does a "good death" look like in the context of inequities?

,,,

What Does A "Good Death" Look Like in the Context of Inequities?

dying at the preferred place

relief from pain and psychological distress

emotional support from loved ones

autonomous treatment decision making

avoidance of futile life-prolonging interventions and of being a burden to others

right to assisted suicide or euthanasia

effective communication with professionals

performance of rituals



















Equity in Palliative Approaches to Care (ePAC) Inner-City Action Team





















Pan-Canadian Research Collaborative

PCOAT

Palliative
Care
Outreach and
Advocacy
Team



PEACH

Palliative Education and Care for the Homeless

(Toronto, ON)

ICHA Inner City
Health Associates



PORT

Palliative Outreach Resource Team

(Victoria, BC)





CAMPP

Community Allied Mobile Palliative Partnership

(Calgary, AB)



PACT

Palliative Advocacy & Care Team

(Thunder Bay, ON)





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?

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









Sneaking someone's cat into the hospital

#thisispalliativecare

Finding a banana for someone who can't eat solid food

#thisispalliativecare

Giving someone Christmas in October

#thisispalliativecare



Going to the store to get cigarettes when someone can't go themselves

#thisispalliativecare



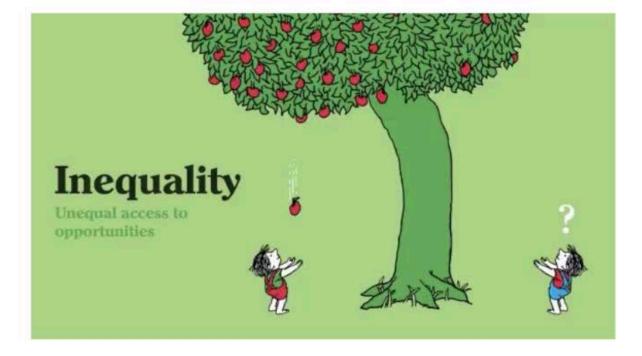
Helping someone get access drugs to help manage their pain

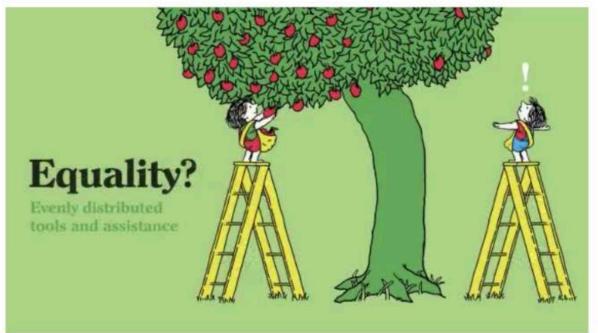
#thisispalliativecare

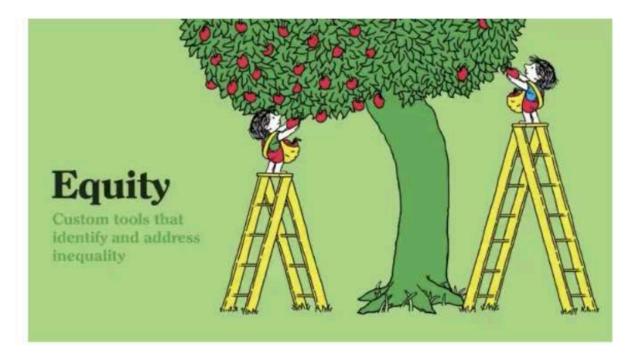


Getting an artist the tools to do their craft

#thisispalliativecare



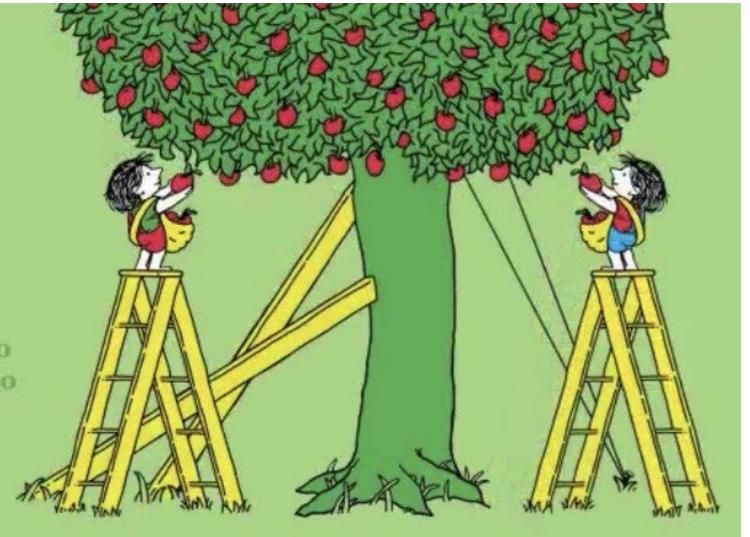




Tony Ruth @lunchbreath

Justice

Fixing the system to offer equal access to both tools and opportunities



Summary of Key Resources

REPORT



Beginning the journey into the spirit world: First Nations, Inuit and Métis approaches to palliative and end-of-life care in Canada. This resource focuses on the challenges and resiliencies of accessing timely and culturally congruent palliative and end-of-life care for First Nations, Inuit and Métis People





Palliative Outreach Resource Team (PORT) Interim Report. This report provides an analysis of service user demographics and service utilization of a consultation-based mobile team in Victoria, BC.







EQUIP Equity Essentials. This resource shares essential messages on equity, categorized into six sections with an accompanying brief video per section. These key messages serve as a foundation for better understanding health equity.

VIDEO



RESEARCH PAPER



Extending Palliative Approaches to
Care Beyond the Mainstream
Health Care System: An Evaluation
of a Small Mobile Palliative Care
Team in Calgary, AB. This evaluation
outlines program activities and guides
program development with the
intention of improving program
sustainability and informing future
palliative equity practices.



VIDEO



Where Are All my Relations? Stories of Indigenous Homelessness in B.C.

This eleven-episode video series explores Indigenous homelessness rooted in Indigenous worldviews and experiences. The series provides a broader understanding of Indigenous homelessness in British Columbia.





Palliative Care Competency

Framework. A curriculum guide for educators and reference manual for people providing palliative care. This framework establishes a minimum national standard for palliative care in Canada.

FRAMEWORK



Innovating Care:

Research and Action for Public Health and Palliative Care

4th International Research Seminar EAPC Reference Group on Public Health and Palliative Care



June 17-19, 2025



University of Victoria, Victoria, B.C., Canada



eapcirs2025@uvic.ca







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Q&A



Kelli I. Stajduhar, PhD, RN, FRSC, FCAHS, FCAN
Professor and Canada Research Chair
Palliative Approaches to Care in Aging & Community
Health, School of Nursing, University of Victoria, Canada
2023/2024 Hood Fellow, University of Auckland



Kate Leahy, BSN, NP (student)
Founding Nurse Coordinator for the Palliative
Outreach Resource Team (PORT), Victoria, BC

Upcoming TeleECHO Sessions

CHCA Project ECHO Rural Connections

All Teach, All Learn Bridging the Knowledge Gap in Isolated Communities





Saving Limbs, Saving Lives: Consensus Guidelines for **Wound Care**

Navigating Arterial Foot Ulcer Care: Practical Guidelines November 19 2024, 11-12pm ET

Bridging Gaps in Diabetic Foot Ulcer Management: Care Strategies December 11 2024, 11-12pm ET

CHCA Project ECHO Integrated Seniors Care

All Teach, All Learn Bridging the Knowledge Gap in Home and Primary Health Care







Building Competencies in Integrated Care: Lessons from Vancouver's Home ViVE Program **December 4 2024, 1-2pm ET**

Register: cdnhomecare.ca/chca-project-echo