Welcome!

We will begin momentarily

Community-Based Primary Palliative Care Community of Practice Series 3

Palliative care for the structurally vulnerable

Project ECHO
Palliative Care - Canada
BY Pallium Canada

Facilitator: Dr. Nadine Gebara

Guest Speaker: Dr. Alissa Tedesco

Date: January 24, 2024

Territorial Honouring

The Palliative Care ECHO Project

The Palliative Care ECHO Project is a 5-year national initiative to cultivate communities of practice and establish continuous professional development among health care providers across Canada who care for patients with life-limiting illness and their families.

Stay connected: www.echopalliative.com

The Palliative Care ECHO Project is supported by a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Health Canada Santé Canada

Project ECHO Palliative Care - Canada BY Pallium Canada

LEAP Core

- Interprofessional course that focuses on the essential competencies to provide a palliative care approach.
- Taught by local experts who are experienced palliative care clinicians and educators.
- Delivered online or in-person.
- Ideal for any health care professional (e.g., physician, nurse, pharmacist, social worker, etc.) who provides care for patients with life-threatening and progressive life-limiting illnesses.
- Accredited by the CFPC and Royal College.

Pallium Canada

LEAP CORE

Learn more about the course and topics covered by visiting

www.pallium.ca/course/leap-core

Objectives of this Series

After participating in this series, participants will be able to:

- Augment their primary-level palliative care skills with additional knowledge and expertise related to providing a palliative care approach.
- Connect with and learn from colleagues on how they are providing a palliative care approach.

Overview of Sessions

Session #	Session Title	Date/ Time
Session 1	Communication: Part 1	Oct 25, 2023 from 12:30-1:30pm ET
Session 2	Communication: Part 2	Nov 29, 2023 from 12:30-1:30pm ET
Session 3	Managing the last hours of life	Dec.20, 2020 from 12:30-1:30pm ET
Session 4	Palliative care for the structurally vulnerable	Jan 24, 2024 from 12:30-1:30pm ET
Session 5	Procedural management of complex pain: Nerve blocks, vertebral augmentation, radiotherapy	Feb 21, 2024 from 12:30-1:30pm ET
Session 6	Terminal Delirium and Palliative Sedation	Mar 27, 2024 from 12:30-1:30pm ET
Session 7	Creative art therapy in palliative care	Apr 24, 2024 from 12:30-1:30pm ET
Session 8	What in store for Palliative Care in Canada: policy, advocacy and implementation	May 29, 2024 from 12:30-1:30pm ET
Session 9	Grief and Bereavement: Beyond the Basics	June 26, 2024 from 12:30-1:30pm ET

Welcome & Reminders

- Please introduce yourself in the chat! Let us know what province you are joining us from, your role and your work setting.
- Your microphones are muted. There will be time during this session when you can unmute yourself for questions and discussion.
- You are welcome to use the chat function to ask questions and add comments throughout the session.
- This session is being recorded and will be emailed to registrants within the next week.
- Remember not to disclose any Personal Health Information (PHI) during the session.
- This 1-credit-per-hour Group Learning program has been certified by the College of Family Physicians of Canada for up to **9 Mainpro+** credits.

Disclosure

Relationship with Financial Sponsors:

Pallium Canada

- Not-for-profit
- Funded by Health Canada

Disclosure

This program has received financial support from:

- Health Canada in the form of a contribution program.
- Generates funds to support operations and R&D from Pallium Pocketbook sales and course registration Fees.

Facilitator/ Presenters:

- Dr. Nadine Gebara: Nothing to disclose
- Dr. Alissa Tedesco: Nothing to disclose.

Disclosure

Mitigating Potential Biases:

- The scientific planning committee had complete independent control over the development of course content.

Introductions

Facilitator:

Dr. Nadine Gebara, MD CCFP- PC
Clinical co-lead of this ECHO series
Palliative Care Physician at Toronto Western Hospital, University Health Network
Family Physician at Gold Standard Health, Annex

Panelists:

Dr. Haley Draper, MD CCFP- PC
Clinical co-lead of this ECHO series
Palliative Care Physician at Toronto Western Hospital, University Health Network
Family Physician at Gold Standard Health, Annex

Dr. Roger Ghoche, MDCM CCFP-PC, MTS
Palliative Care and Rehabilitation Medicine, Mount Sinai Hospital- Montreal

Jill Tom, BSN CHPCN ©
Nurse Clinician for palliative Home Care
Mount Sinai Hospital, Montreal

Introductions

Panelists (continued):

Elisabeth Antifeau, RN, MScN, CHPCN(C), GNC(C)
Regional Clinical Nurse Specialist (CNS-C), Palliative End of Life Care
IH Regional Palliative End of Life Care Program
Pallium Canada Master Facilitator & Coach, Scientific Consultant

Thandi Briggs, RSW MSW
Care Coordinator, Integrated Palliative Care Program
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Claudia Brown, RN BSN
Care Coordinator, Integrated Palliative Care Program
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Rev. Jennifer Holtslander, SCP-Associate, MRE, BTh
Spiritual Care Provider

Support Team

Aliya Mamdeen
Program Delivery Officer, Pallium Canada

Diana Vincze
Palliative Care ECHO Project Manager, Pallium Canada

Introductions

Guest Speaker:

Dr. Alissa Tedesco, MD, CCFP(PC)

Palliative Care Physician, Temmy Latner Centre for Palliative Care, Sinai Health System
Palliative Care Physician & Deputy Lead, Palliative Education and Care for the Homeless (PEACH), Inner City Health Associates
Assistant Professor, Department of Family & Community Medicine, University of Toronto

Palliative Care for Structurally Vulnerable Populations: Understanding & Addressing Barriers to Care

Session Learning Objectives

Upon completing the session, participants will be able to:

1. Describe the concept of structural vulnerability and its implications for the delivery of equitable palliative care.
2. Identify how we can address barriers to quality palliative care through socially accountable practice.
3. Develop an understanding of trauma-informed care and harm reduction and how to apply them to palliative care practice.

Who faces barriers to quality palliative care?

What are these barriers?

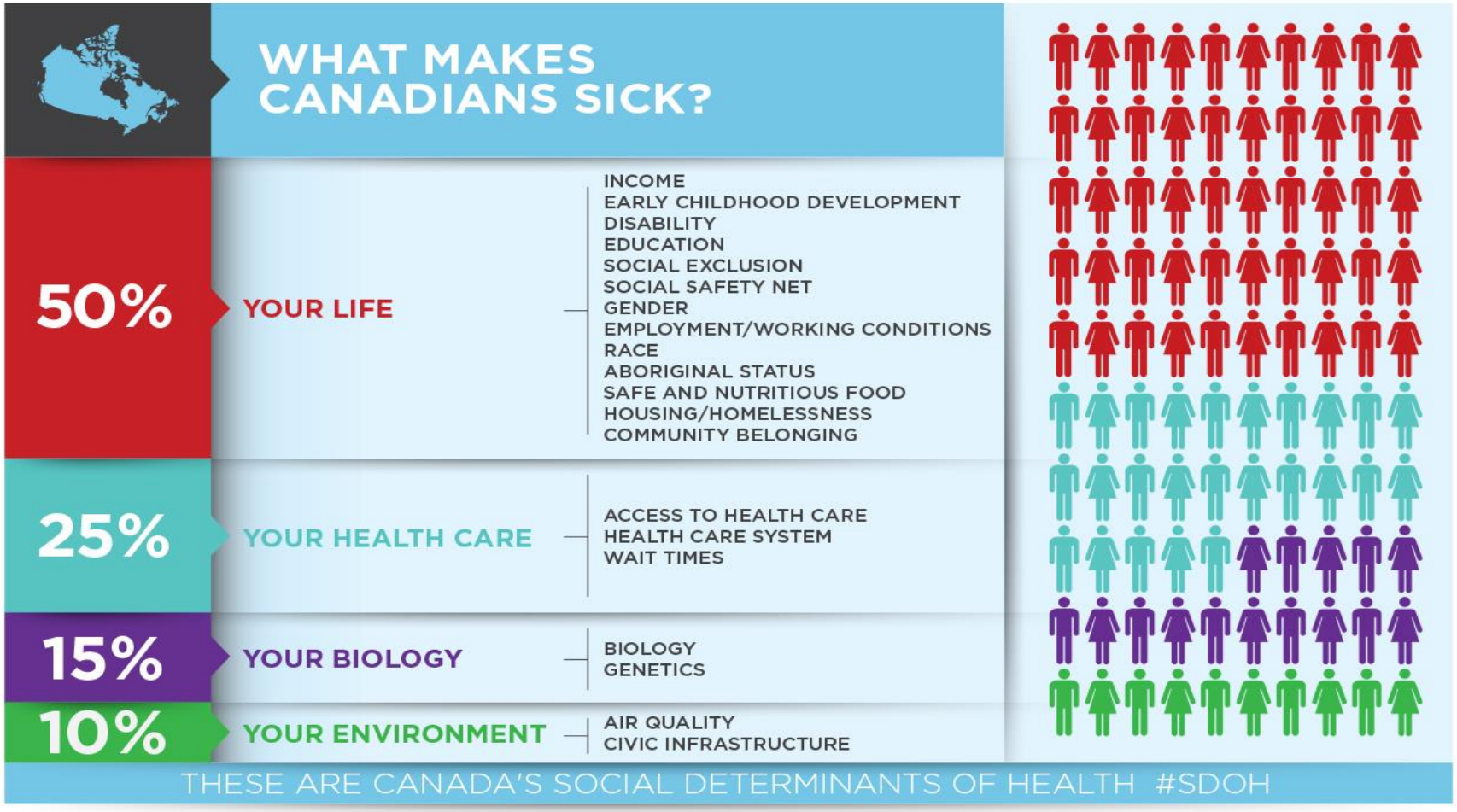
Case Study: Susan

49-year-old woman recently diagnosed with metastatic rectal cancer

- Experienced homelessness for many years, currently couch-surfing with a friend
- Remote history of opioid use disorder (OUD), no current drug use
- She was declined potentially curative chemoradiation therapy due to her “social circumstances” when she was stage 3 and had since been “lost to follow-up”
- She currently has severe rectal pain, and is only on Tylenol #3 for analgesia
- She is a candidate for palliative radiation as an outpatient and is being discharged soon

You meet her for a palliative care consultation on an inpatient unit.

What makes us sick?



Canadian Medical Association, 2015

What makes us sick?

Rai, N.

Structural Vulnerability

"when location within social, economic, and political hierarchies, as well as power dynamics limit agency and produce vulnerability to risk and harm among particular groups"

Stajduhar K et al, 2018

‘Double’ Vulnerability

Advances in Nursing Science
Vol. 39, No. 4, pp. 293–307

Death Is a Social Justice Issue

Perspectives on Equity-Informed Palliative Care

Sheryl 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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Stajduhar et al. Too Little Too Late: How we fail vulnerable Canadians as they die and what to do about it. U Vic Institute on Aging & Lifelong Health. https://www.virtualhospice.ca/Assets/report-too-little-too-late_20210618100943.pdf

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Key Findings

- The survival imperative
- The normalization of death
- Recognizing the need for PC services
- Silos to bring down, cracks to fill
- Risk management as a barrier to aging in place and dying at home
- A bereaved community, supporting workers and ‘chosen family’
- Justice at EOL for some

Recommendations

1. Address barriers in formal HC settings that prevent people experiencing SVs from receiving diagnosis, treatment, support and care.
2. Integrate palliative approaches to care where people experiencing SV live and die.
3. Support non-traditional families (e.g. street family, inner city workers) and include in decision making processes and care strategies.

Essential skills for caring for structurally vulnerable populations

Recognizing and Addressing Barriers to Care

Rai, N.

Important to explore, anticipate and address barriers to ongoing care

Reflect on your and your institution's roles in addressing or exacerbating barriers

Case Study: Susan

49-year-old woman recently diagnosed with metastatic rectal cancer

- Experienced homelessness for many years, currently couch-surfing with a friend
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- She was declined potentially curative chemoradiation therapy due to her “social circumstances” when she was stage 3 and had since been ”lost to follow-up”
- She currently has severe rectal pain, and is only on Tylenol #3 for analgesia
- She is a candidate for palliative radiation as an outpatient and is being discharged soon

You meet her for a palliative care consultation on an inpatient unit.

Back to the Case

You do a thorough social history, and you discover that Susan:

- Doesn’t have a phone
- Is paying out of pocket for transportation to the hospital (taxi)
- Her living situation with her friend is unstable
- She is on Ontario Works (basic provincial welfare) for income support
- She has a son who she hasn’t been in touch with for a couple years

She is going to be discharged soon but you plan to follow her as an outpatient.

How can you intervene to address some of her barriers to care?

Trauma-Informed Care

Affects how and if people access care, how they relate/interact with others, how they cope

"**Trauma-informed services** take into account an understanding of trauma in all aspects of service delivery and place priority on physical and emotional **safety**, as well as **choice** and **control** in decisions affecting one's treatment."

Healthcare is a place where trauma and retraumatization can occur

Trauma-Informed Language

- Use words that are value-neutral
- Put people first
- Preferred names/pronouns

Stigmatizing language perpetuates negative perceptions

Health Quality Ontario

Let's make our health system healthier

Ontario Health Quality Ontario

Guidance for Language around Substance Use

Terms to use	Terms to avoid
Addiction	Abuse
Currently using substances	Abuser
Craving	Addict
Dependence	Alcoholic
Detoxification	Clean
Excessive (use)	Detox
Heavy (use)	Dirty
Medication-assisted recovery	Habit
Misuse	Problem
Negative (for a toxicology screen)	Smoker
Not currently using substances	User
Opioid	
Positive (for a toxicology screen)	
Person who smokes	
Person who uses drugs	
Person with an addiction	
Person with a substance use disorder	
Recovery	
Remission	
Risky (use)	
Substance use disorder	
Treatment	
Unhealthy (use)	
Use	
Withdrawal	

Back to the Case

On one of your subsequent visits Susan tells you that her friends call her Sammy. She tells you her given name reminds her of a difficult childhood in foster care where she suffered from abuse.

You thank her for telling you and apologize for not asking when you first met. You let her know you will call her Sammy moving forward and will let the rest of the care team know.

Case Study: Sammy

You go on to follow Sammy in your hospital's outpatient clinic.

She is now on ODSP (Ontario Disability Support Program).

You're advised she recently presented to the ED. You can see on Connecting Ontario that she presented with syncope and severe pain and was found to be severely anemic. She left "AMA" before she was able to get a transfusion.

What do you think is going on?

How might trauma be impacting this interaction?

A Trauma-Informed Lens

From (deficit perspective)	To (trauma-informed & strengths-based)
What is wrong?	What has happened?
Symptoms	Adaptations
Disorder	Response
Attention seeking	The individual is trying to connect in the best way they know how
Borderline	The individual is doing the best they can given their early experiences
Controlling	The individual seems to be trying to assert their power
Manipulative	The individual has difficulty asking directly for what they want
Malingering	Seeking help in a way that feels safer

Table 2. Trauma-Informed Care Actions for Physicians

Previsit

Review the patient's chart for trauma-related documentation to avoid asking the patient to repeat this history and to improve visit preparation

Encounter

Be seated to decrease the existing power differential between physicians and patients; encourage residents, students, or other present staff to also be seated

Offer options for the patient to be interviewed alone (e.g., have support staff care for accompanying children)

Emphasize confidentiality as the encounter begins

Prepare the patient for what to expect with regard to history, examination, and any procedures

Make the patient aware that you may be taking notes during the encounter to ensure thoroughness in addressing all questions and concerns

Explain the rationale for sensitive questions, such as when eliciting substance use and sexual history

If a language interpreter is being used, when possible, ask if the patient has a gender and/or cultural preference for the interpreter

Physical examination

Ask patients if there are any parts of the physical examination that they feel anxious about, and if there is anything you can do to help make the physical examination feel more comfortable

Ask the patient to shift his or her clothing out of the way instead of doing it yourself (e.g., lifting his or her own shirt for an abdominal examination)

Ask the patient for permission before conducting each section of physical examination (e.g., when moving from heart to lung examination)

Invasive examinations and procedures

Determine whether alternate measures can be taken for certain examinations (e.g., offering self-insertion of swabs for vaginitis workup instead of speculum examination)

Ask whether the patient would like to have another person in the room for support

Describe the entire procedure, obtain consent, and set up the appropriate equipment (e.g., remove packaging from swabs and Papanicolaou smear containers, and apply lubrication on scopes or speculums) before the patient removes clothing

Describe ways in which the examination may interact with senses (e.g., "You may hear clicks when the speculum is opened"; "The lubrication on the speculum/anoscope may feel cool"; or "You may experience a gagging sensation with the throat swab")

Discuss in advance that the patient can dictate the pace of the examination and can signal to you (through verbal or nonverbal signals) if there is any discomfort or a break is needed

Offer speculum self-insertion

Practice suggestive instead of instructive language (e.g., replace the phrase "Take a deep breath and relax" with "Some people find it helpful to take a deep breath during this part of the examination")

Have postprocedure supplies ready to provide to patient (e.g., tissues or wipes following speculum examination or anoscope)

Imaging

Alert the patient in advance if imaging may be invasive (e.g., transvaginal or scrotal ultrasonography), constrictive (e.g., magnetic resonance imaging), or weighted (e.g., lead aprons for chest radiography)

Referrals

Notify referrals in advance regarding relevant trauma history so colleagues are appropriately prepared

Postvisit

Provide written after-care instructions and follow-up plan in case patients experience dissociation or distracting anxiety during the visit

Choose sensitive language for diagnoses in visit summaries that are provided to patients and in documentation

Information from references 3, 4, and 11 through 13.

SPECIAL FEATURES: CLINICAL CONCEPTS

WILEY PHN PUBLIC HEALTH NURSING

Advance care planning with individuals experiencing homelessness: Literature review and recommendations for public health practice

Sarah A. Hubbell DNP(c), MSN, RN, CNL

Engaging Homeless Persons in End of Life Preparations

John Song, MD, MPH, MAT[1,3], Melanie M. Wall, PhD[2], Edward R. Ratner, MD[1,3], Dianne M. Bartels, RN, PhD[1,3], Nancy Ulvestad, BSN, MART[1], and Lillian Gelberg, MD, MSPH[4]

[1]Center for Bioethics, University of Minnesota, Minneapolis, MN, USA; [2]Division of Biostatistics, University of Minnesota School of Public Health, Minneapolis, USA; [3]Department of Medicine, University of Minnesota Medical School, Minneapolis, USA; [4]Department of Family Medicine, David Geffen School of Medicine at UCLA, Minneapolis, USA.

ARTICLE

Annals of Internal Medicine

Effect of an End-of-Life Planning Intervention on the Completion of Advance Directives in Homeless Persons

A Randomized Trial

John Song, MD, MPH, MAT; Edward R. Ratner, MD; Melanie M. Wall, PhD; Dianne M. Bartels, RN, PhD; Nancy Ulvestad, BSN, MART; Dawn Petroskas, BSN; Melissa West, MD; Anne Marie Weber-Main, PhD; Leah Grengs; and Lillian Gelberg, MD, MSPH

JOURNAL OF PALLIATIVE MEDICINE
Volume 8, Number 1, 2005

Attitudes, Experiences, and Beliefs Affecting End-of-Life Decision-Making Among Homeless Individuals

ANITA J. TARZIAN, Ph.D., R.N.,[1] MAGGIE T. NEAL, Ph.D., R.N.,[2] and J. ANNE O'NEIL, Ph.D., M.S.N.[3]

Original Article

PALLIATIVE MEDICINE

Chronically homeless persons' participation in an advance directive intervention: A cohort study

Palliative Medicine
2015, Vol. 29(8) 746–755

DOI: 10.1177/0269216315575679
pmj.sagepub.com
SAGE

Alexander K Leung[1], Dhruv Nayyar[1], Manisha Sachdeva[1], John Song[2] and Stephen W Hwang[1,3]

ACP/GOC for SV Populations

- Rarely completed, if at all
- Frequent experiences with death
- A ‘survival focus’ (e.g.: 94% chose to receive CPR)
- Mistrust of healthcare systems, providers
- Beliefs that wishes will not be respected, that care will be poor at EOL
- Fear of dying alone, anonymously, worries about bodily remains
- Lack of POA/SDM, advocates

Harm Reduction

"Harm reduction refers to policies, programmes and practices that aim to ***minimise negative health, social and legal impacts associated with drug use, drug policies and drug laws…*** *Harm reduction is* ***grounded in justice and human rights*** *- it focuses on positive change and on working with people* ***without judgement, coercion, discrimination, or requiring that they stop using drugs as a precondition of support****."*

Harm Reduction international

"Enhances the ability of people who use substances to have ***increased control*** *over their lives and their health, and allows them to take* ***protective and proactive measures for themselves, their families and their communities****"*

Streetworks (Edmonton)

Key Principles:

- Non-judgement
- Practical interventions = small steps to reduce harm (a spectrum)
- Client-centered approach = meeting people where they're at

Harm Reduction Programming

Examples:

- Managed alcohol programs (MAP)
- Needle and crack-kit distribution programs
- Supervised consumption sites (SCS), overdose prevention sites (OPS)
- Safer supply

What does harm reduction look like in practice?

Case Study: Sammy

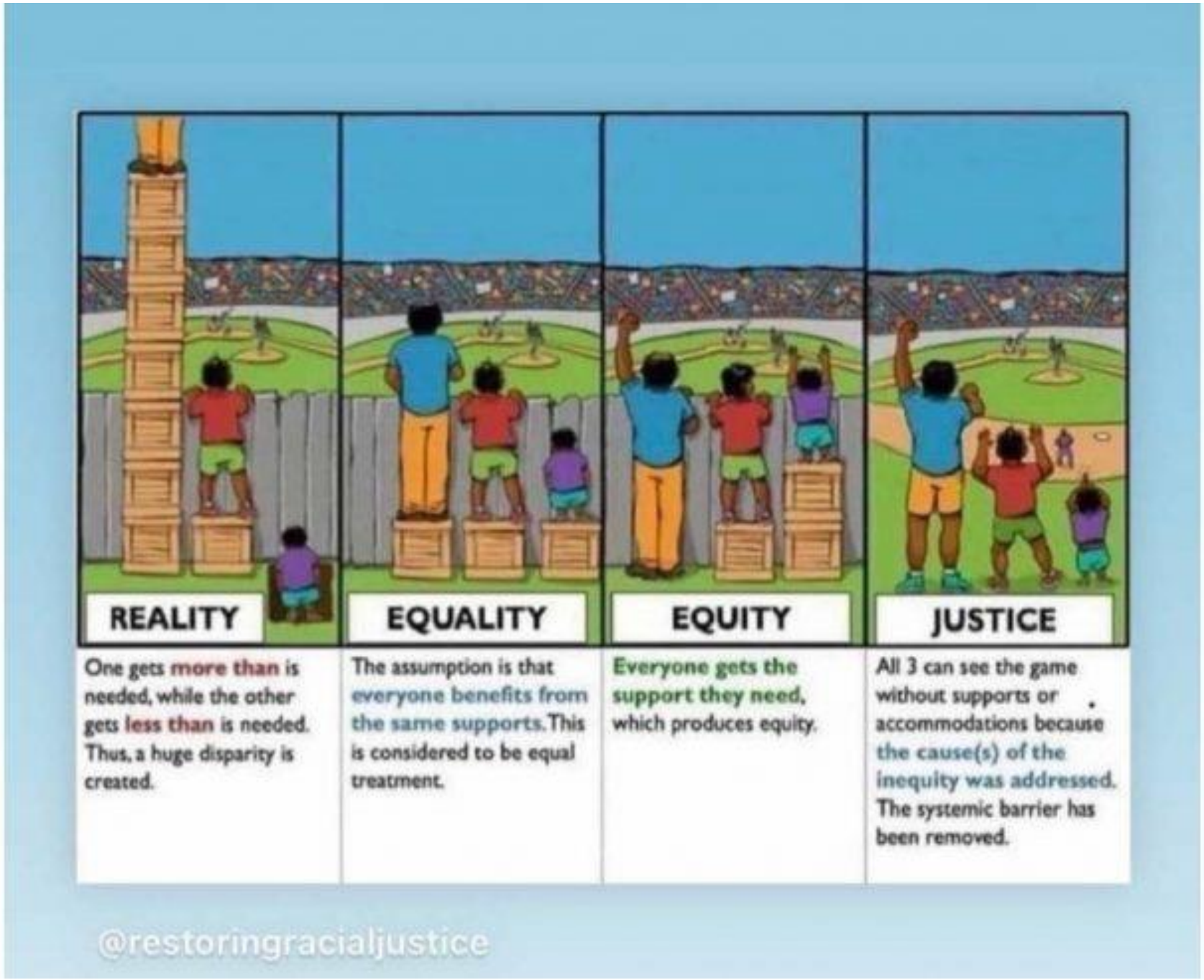
You were eventually able to secure Sammy her own apartment through Terminal Illness Priority. She is able to live there independently for a number of months. She spends a lot of time with her son after being reconnect with him.

Over the last two weeks she has become weaker and is having a hard time getting out of bed. Her son is getting paid under the table and isn't able to be there as much as he would like to help with caregiving. She has maxed out PSW and nursing supports. Her pain has also been getting worse and she has been having rectal bleeding. It is not within her goals of care to go to ED. She is open to applying to PCU but is hesitant given the many negative experiences she has had in institutions.

You apply to a number of PCUs. You find you are being asked more screening questions about her mental health and substance use than you might normally expect. She is declined from two PCUs due to "behavioural concerns."

Have you seen this happen before to your patients?

How could our institutions and programs be more trauma-informed?


REALITY
EQUALITY
EQUITY
JUSTICE
One gets more than is needed, while the other gets less than is needed. Thus, a huge disparity is created.
The assumption is that everyone benefits from the same supports. This is considered to be equal treatment.
Everyone gets the support they need, which produces equity.
All 3 can see the game without supports or accommodations because the cause(s) of the inequity was addressed. The systemic barrier has been removed.
@restoringracialjustice

What would justice have looked like for Sammy?

- Adequate social assistance programs
- Higher minimum wage
- Access to affordable housing
- Harm reduction and trauma-informed practices in institutions
- Equitable allocation of home care and caregiving supports
- Full access to comprehensive health care
- …

An early diagnosis of cancer with appropriate treatment so that she wouldn't need palliative care at the age of 49

Conclusions:

- Social and structural factors define health, wellbeing and our experiences of living and dying.
- Exploring your patient's social context will allow you to better align your agenda with your patients allows you to identify, anticipate and address barriers to care.
- Trauma-informed care and harm reduction are skillsets and philosophies that enable you to provide care that is truly person-centered.

Questions?

Contact: alissa.tedesco@mail.utoronto.ca

Session Wrap Up

- Please fill out our feedback survey, a link has been added into the chat.
- A recording of this session will be emailed to registrants within the next week.
- We hope to see you again at our next session taking place **February 21st, 2024 from 12:30-1:30pm ET** on the topic of **Procedural management of complex pain: Nerve blocks, vertebral augmentation, radiotherapy.**
- Thank you for your participation!

Thank You

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