

Compassionate Care Continuum

Addressing Ageism and Ableism in Pediatric Palliative Care and Palliative Care in Long-Term Care



BY
Pallium Canada

Host: Diana Vincze, Pallium Canada

Presenter: Dr. Amit Arya, MD CCFP (PC), FCFP

Dr. Stephanie van Zanten MD, FRCPC (Pediatrics)

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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.

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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.



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.



Learn more about the course and topics covered by visiting

www.pallium.ca/course/leap-core

Welcome & Reminders

- For comments, please use the chat function.
- For questions, please use the Q&A function.
- 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.

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.

Host/ Presenters:

- Diana Vincze: Nothing to disclose.
- Dr. Amit Arya: Nothing to disclose
- Dr. Stephanie van Zanten: Nothing to disclose.

Disclosure

Mitigating Potential Biases:

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

Introductions

Host

Diana Vincze

Palliative Care ECHO Project Manager, Pallium Canada

Presenters:

Dr. Amit Arya, MD CCFP (PC), FCFP

Medical Director, Specialist Palliative Care in Long-Term Care Outreach Team, Kensington Health, Toronto
Palliative Care Physician, Freeman Centre for the Advancement of Palliative Care, North York General Hospital
Lecturer, Division of Palliative Care, Department of Family and Community Medicine, University of Toronto
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(Pediatrics)
Pediatric Palliative Care Team Physician
Children's Hospital of Eastern Ontario and Roger Neilson House Children's Hospice
Assistant Professor, University of Ottawa

Session Learning Objectives

Upon completing the session, participants will be able to:

- To gain increased understanding of how ageism and ableism impact the practice of palliative care
- To appreciate how our long-term care system, by its very design and history, is ableist
- To understand how our healthcare system discriminates against children and families with disabilities

Addressing Ageism and Ableism in Pediatric Palliative Care and Palliative Care in Long-Term Care

INTERNATIONAL DAY OF PERSONS WITH DISABILITIES



More disclosures!

Definitions

Ableism

The discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior

Ageism

Ageism refers to the stereotypes (how we think), prejudice (how we feel) and discrimination (how we act) towards others or oneself based on age

Ageism in Pediatrics

Personhood

“Validation at all stages of parenthood, and of their baby’s’ personhood is central to the experience of parents.”

Tatterton & Fisher 2023



Ageism and Ableism

The prevalence of disability increased with age: 13% for those aged 15 to 24 years to 47% for those aged 75 years and over

Risk of moderate to severe NDD increases with decreasing gestational age in extremely premature infants, 24% at 25 wks GA and 43% at 22wks

Intersectionality



How often do you think about the impact of ageism and ableism on your patients?

“Mary”





Dr. Amit Arya 

@AmitAryaMD



Eldercare (LTC & home care) spending in OECD countries as a percentage of GDP:

1. Netherlands: 3.7%
2. Norway: 3.3%
3. Sweden: 3.2%
4. Denmark: 2.5%
5. Canada: 1.3% (and JUST 0.2% of that on home care!)

When will Canada stop underfunding eldercare...& also prioritize homecare?

“A culture of institutionalization”

Problems with institutionalization

- Congregation- unnatural
- Loss of identity
- Standardization, regimentation
- Loss of control
- Dislocation from home and community
- Loss of abilities



“Warehousing”

“We can’t build our way out of the
eldercare crisis”

“A broken system”

- Staffing shortages, poor working conditions, high turnover
- Lack of training and education in geriatrics and palliative care
- Not enough physician involvement
- Little transparency and accountability
- Many for-profit providers




The Need for Palliative Care in LTC

- For nearly 100% of people in LTC, it is their last home prior to death
- People are in declining health when they are admitted to LTC (average life expectancy is 18 months)
- Annual mortality rate in LTC is 27-52.3%

81% of LTC residents had no record
of palliative care in their last year of
life

Fact: Only 1 in 8 LTC residents were able to see a palliative care specialist in their last year of life



Let's start thinking of long-term care homes as “**long-term palliative care homes.**” So much of long-term care IS palliative care.

QOL

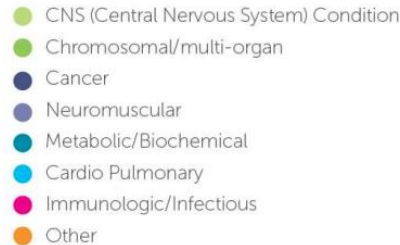
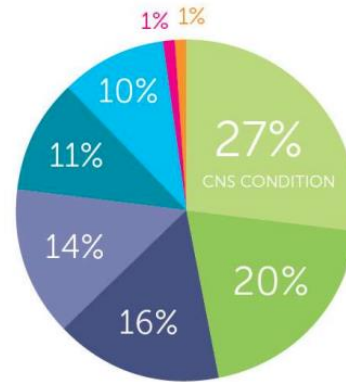
Disability paradox



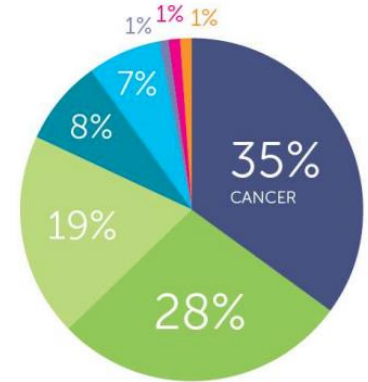
Pediatric Palliative Care Snapshot

- End of life care
- Symptom management
- Transitions
- Respite

Diagnostic Categories for Children on CPCH Program



Deaths on Program by Diagnostic Group



Travis

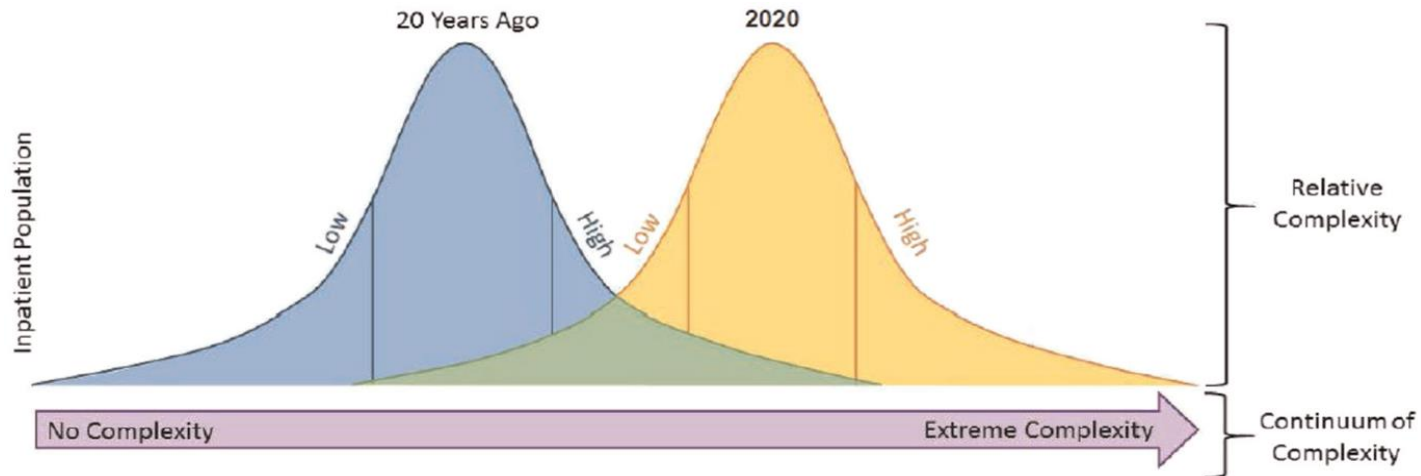


Amis Instantanés - HM O'Connor & C Davila

Children with Medical Complexity (CMC)

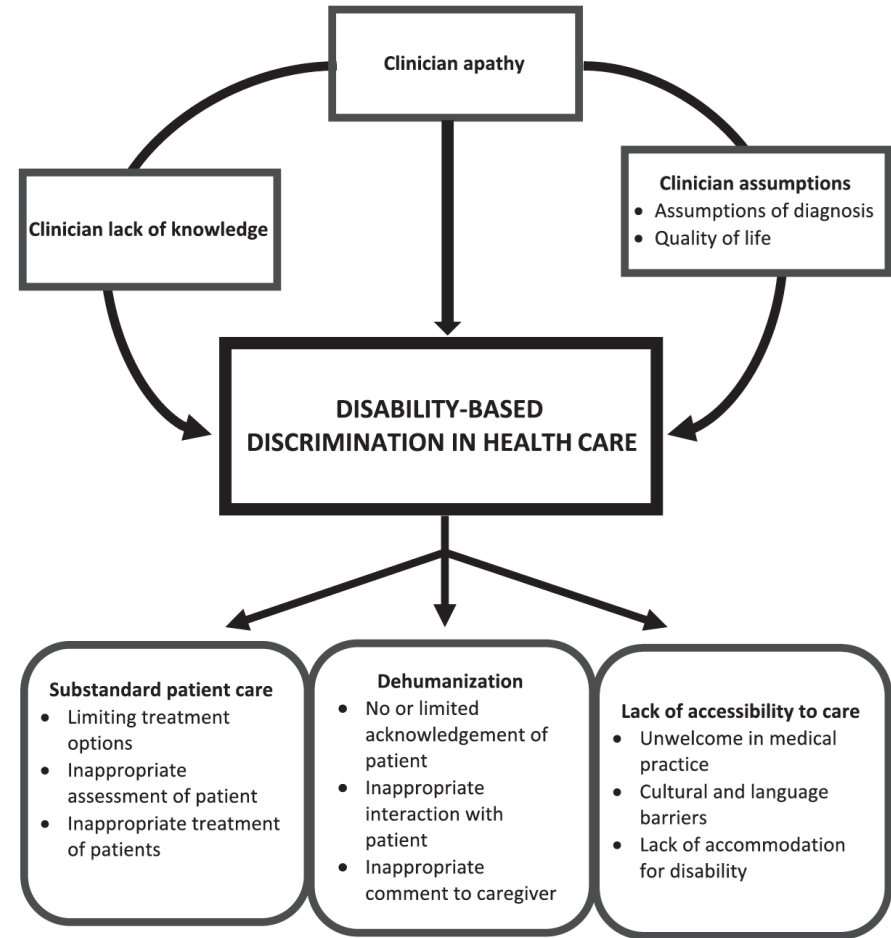
- No consensus on definition
- Many have technology dependence and/or disability
- Frequent encounters with HC
- Increasing number of kids

Rogers et al. 2021



Perceived Drivers of Discrimination from Clinicians

Manifestations of Discrimination



- Care Coordination
- Supports
- Transitions



QOL

Disability paradox



YES

NO

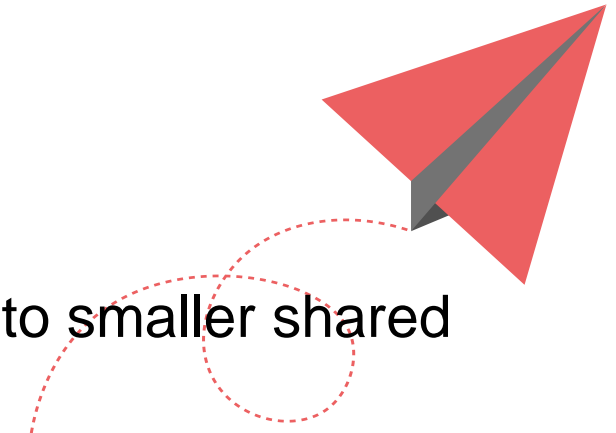


Common Threads

- Population that is often unable to consent for themselves (or it is assumed that they lack all capacity)
- Staffing concerns
- Lack of education and training
- Disparities based on race, ethnicity, language, location, gender, sexual orientation

The way forward

- Increase funding for home care
- Make the change from large LTC homes to smaller shared homes and more supportive housing
- Build more residential pediatric hospices (for respite as well)
- Improve working conditions
- Ensure all staff are trained in geriatrics and palliative care
- Support essential caregivers
- Increase transparency and accountability
- Legislation to support change



Conclusions

- Palliative care is a disability justice issue
- Holistic approach to relief of suffering
- Healthcare team duty to use their position to create change

References available upon request

Q & A



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.
- Thank you for your participation!

Thank You



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