CHCA Project ECHO
Home-Based Palliative Care

All Teach, All Learn

Bridging the Knowledge Gap in
Home-Based Palliative Care

Compassionate Care in Last Days and Hours

Anticipating End of Life:
Competencies for Compassionate, Person-Centred Care

Dr. Sarina Isenberg, PhD, MA, Chair in Mixed Methods Palliative Care Research, Bruyère Research Institute, Associate Professor, Department of Medicine, and School of Epidemiology and Public Health, University of Ottawa
Dr. Lisa Boucher, **PhD**, Postdoctoral Fellow, Bruyère Health Research Institute Faculty of Medicine, University of Ottawa
Kyle Drouillard, MSc, BSc Psych, Research Coordinator, Bruyère Health Research Institute

Host: Jennifer Campagnolo, Canadian Home Care Association
October 15, 2025

Land Acknowledgement

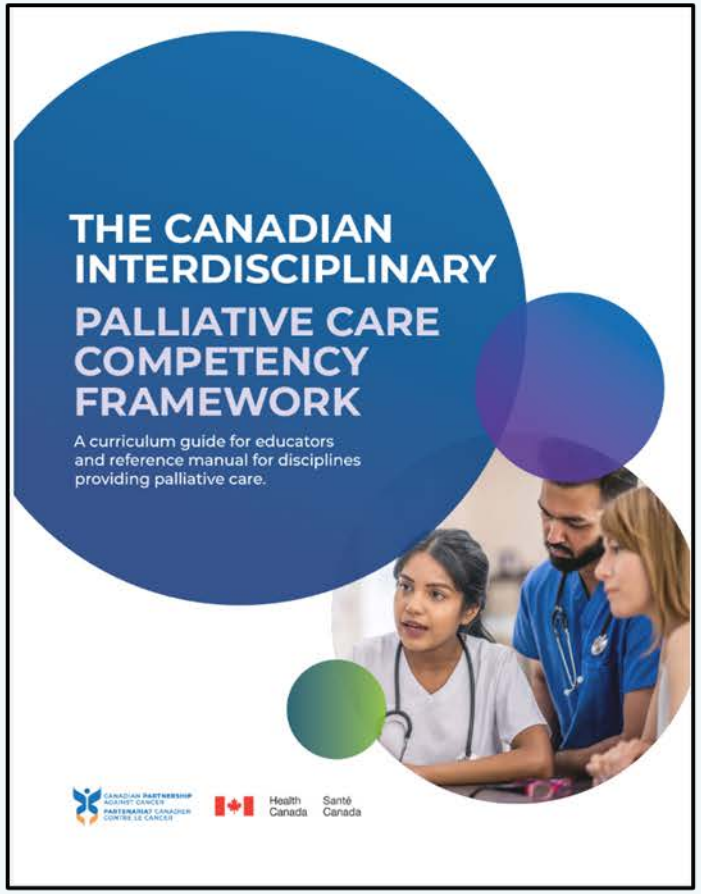
Artist Credit: Patrick Hunter

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.
- Multilingual 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



Compassionate Care in Last Days and Hours

Domain 6: Last Days and Hours

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:

- **Anticipate, recognize and respond** to physical, emotional, and spiritual needs and barriers to care with action and compassion.
- **Practice cultural humility**—reflect, adapt, and address bias and inequity.
- **Collaborate with families and communities** to honour cultural and spiritual rituals.
- **Communicate clearly and empathetically** with inclusive, respectful language.
- **Advocate for dignity and equity** in every aspect of end-of-life care.

[1] Canadian Partnership Against Cancer & Health Canada. *The Canadian Interdisciplinary Palliative Care Competency Framework.* Toronto, ON: 2021.

Introductions

Dr. Sarina Isenberg, PhD, MA
Chair in Mixed Methods Palliative Care Research,
Bruyère Research Institute
Associate Professor, Department of Medicine,
and School of Epidemiology and Public Health,
University of Ottawa

Dr. Lisa Boucher, PhD
Postdoctoral Fellow
Bruyère Health Research Institute
Faculty of Medicine,
University of Ottawa

Kyle Druillard, MSc, BSc Psych
Research Coordinator
Bruyère Health Research Institute

Systemic Barriers and Inclusive Solutions

Dr. Sarina Isenberg
Principal Investigator, Isenberg Lab
Bruyère Chair in Mixed Methods Palliative Care Research | Bruyère Health Research Institute
Associate Professor | Department of Medicine | University of Ottawa

Dr. Lisa Boucher
Postdoctoral Fellow, Isenberg Lab | Bruyère Health Research Institute
Faculty of Medicine | University of Ottawa

Kyle J. Drouillard
Research Coordinator, Isenberg Lab
Bruyère Health Research Institute

About us

Sarina Isenberg

- Bruyère Chair in Mixed Methods Palliative Care Research
- Associate Professor in the Faculty of Medicine at University of Ottawa

Lisa Boucher

- Postdoctoral Fellow
- Equity-focused research on socioeconomic marginalization and communities with complex care needs

Kyle Drouillard

- Research Coordinator
- Equity-focused health research with 2S/LGBTQIA+ populations focusing on bodily autonomy, choice, dignity, and safety

Learning objectives

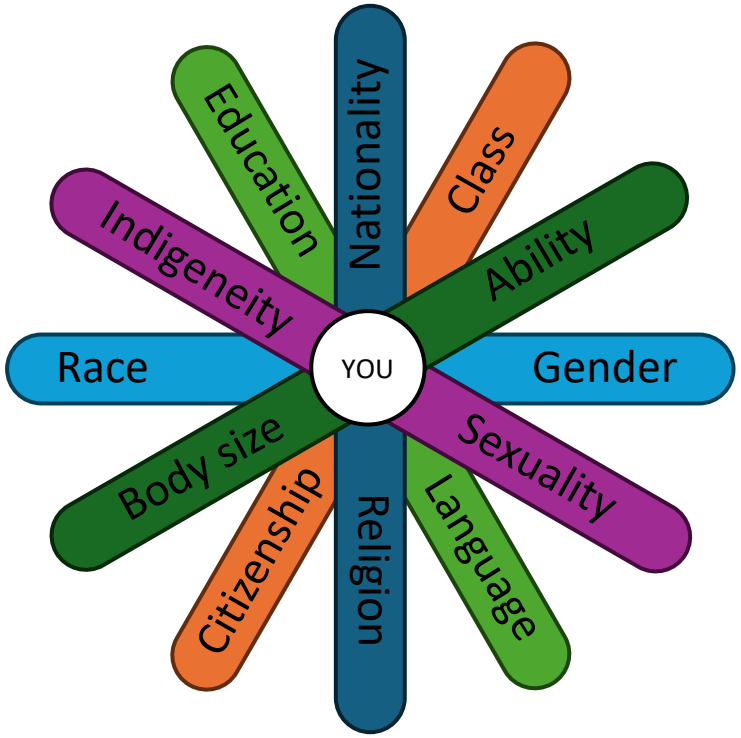
1. **Address** barriers to equitable, culturally respectful end-of-life home care
2. **Equip** home care providers with knowledge and skills to deliver equitable, inclusive, and culturally and spiritually respectful end-of-life care
3. **Promote** cultural competency through community collaboration and flexible, person-centred care to meet holistic end-of-life needs

Method

- Literature on end-of-life home care for equity-deserving groups
  - Special thanks to **Tu Van Anh Tran** for searching, summarizing, synthesizing
  - E.g., “Top 10 Tips for Caring for X Group”
- Communities are not a monolith
  - One-size-fits-all approach is problematic
- Individuals need individual care
  - Intersectional feminist approach sees people in all their complexity
- Higher-level discussion about equitable and inclusive home care
- Reference list provided for deep dive into specific communities

Intersectionality

- People are more than the sum of their parts
- Identities intersect with systems to create unique conditions of power and oppression
- People who live at the intersections of multiply marginalized positions experience health inequities



Power and oppression

Non-white	Skin colour	White
Non-Canadian	Nationality	Canadian by birth
Non-Christian	Religion	Christian
Non-heterosexual	Sexuality	Heterosexual
Non-English	Language	Native English
Transgender, women, non-binary	Gender	Cisgender man
Not formally educated	Education	Doctorate
Fat	Body Size	Thin/“Fit”

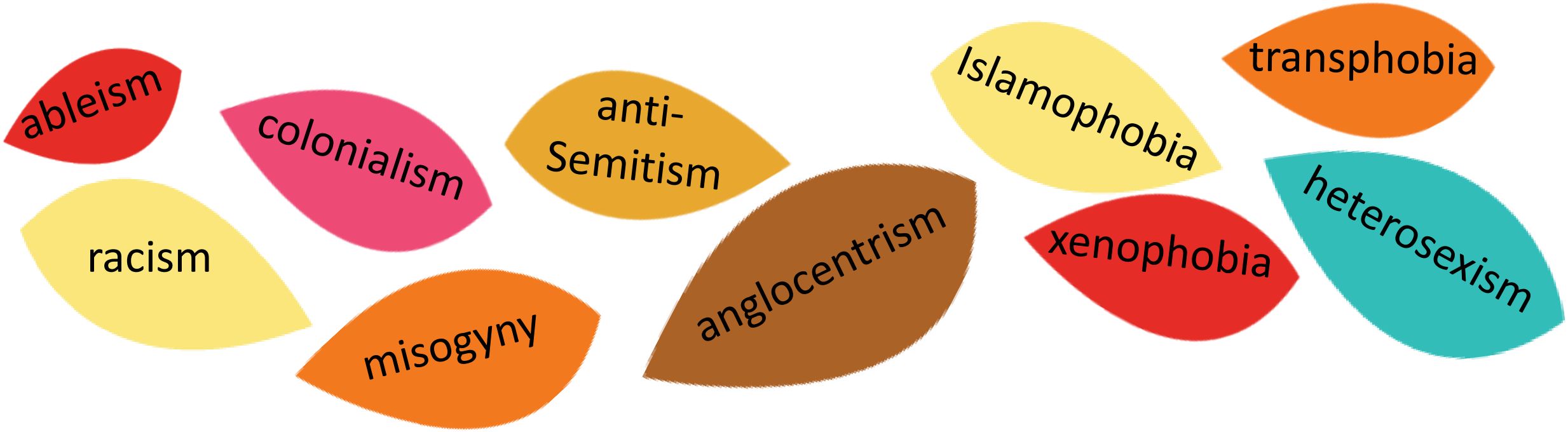
Learning objective

1. **Address** barriers to equitable, culturally respectful end-of-life home care

Barriers to Equity in care

Systemic & Institutional

- The –isms and –phobias that perpetuate systemic oppression
- Policy and funding that contributes to health inequity in practice
- Require institutional and systems change



Access & Inclusion

- Geographic isolation (e.g., rural and Indigenous peoples)
- Low health literacy, familiarity, resources
- Legal, documentation issues

Cultural & Communication

- Implicit bias, stereotyping, and assumptions
- Language barriers
  - Language, accent, communication styles
- Misalignment between medical models and culture
- Disregard for non-dominant (i.e., non-Christian) spiritual needs

Trust & Safety

- Historical trauma, mistrust of institutions
- Fear of discrimination
- Exclusion from decision-making

Learning Objective

2. **Equip** home care providers with knowledge and skills to deliver equitable, inclusive, and culturally and spiritually respectful end-of-life care
3. **Promote** cultural competency through community collaboration and flexible, person-centred care to meet holistic end-of-life needs

ISENBERG LAB

Attitudes

- Cultural humility, respect
- Openness to diverse family and spiritual needs
- Non-judgemental curiosity
- Respect for autonomy and dignity
- Collaborative mindset
- Commitment to justice and equity

Skills - ICCARE

1. **I**ntegrate with and know your communities
2. **C**ollaborate with community leaders to build trust
3. **C**ommunicate clearly, inclusively, and respectfully
4. **A**ccommodate end-of-life practices
5. **R**esource navigation with patients, families, caregivers
6. **E**ngage families and communities in care

Integrate with community

- Know your community
- What are their specific experiences and needs?
- There is no one-size-fits-all approach
- Integrating with community will help meet their needs

Collaborate to build trust

- Get to know community leaders and organizations
- Build trust with people with institutional trauma
- Develop knowledge necessary to understand patients/families
- Better integrate patients and families into care

Communicate clearly

- Be proactive
- Clear, accessible language
- Involve translators for non-English speakers
- Trauma -informed communication
- Inclusive, affirming, non-judgemental language
- Affirming and respectful documentation
- Flexibility in delivering information

Accommodate practices

- Integrating culturally important end-of-life care practices
- Flexible, sensitive, responsive to patient/family needs
- Facilitate cultural- and religion-specific rituals, e.g.,
  - Body washing
  - Body orientation
  - Prayer
  - Displaying sacred symbols

Resource navigation

- Be aware of supportive social and legal services
  - Bereavement support
- Creativity and flexibility is crucial
- Mobilize lay caregivers, volunteers, and staff with cultural and linguistic knowledge
- Involve patient navigators, elders, spiritual leaders

Engage in inclusive care

- Respect collective decision-making practices
- Allow caregivers to maintain control where possible
- Have clear conversations early and often to set expectations
- Expand definition of family

Wrap-up

- Systemic and institutional barriers perpetuate health inequities
- Challenge systems and provide inclusive care in flawed system
- Approach with humility, respect, non-judgemental curiosity, and a collaborative mindset
- Be flexible to individual cultural, spiritual needs
- Remember:
- **I**ntegrate, **C**ollaborate, **C**ommunicate, **A**ccommodate, navigate **R**esources, **E**ngage

- Abdelaal M, Blake C, Lau J. Challenges of Providing Palliative and End-of-Life Care to Refugee Claimants in Canada: A Case Report. Journal of Palliative Medicine. 2021 Apr;24(4):635–8.
- Berkman C, Stein GL, Godfrey D, Javier NM, Maingi S, O'Mahony S. Disrespectful and inadequate palliative care to lesbian, gay, and bisexual patients. Palliative & Supportive Care. 2023 Oct;21(5):782–7.
- de Boer AF, de Voogd X, Meershoek A, Suurmond JL. Dignity-conserving palliative care in a diverse population: A qualitative study of physicians' perspective. Palliative & Supportive Care. 2022 Apr;20(2):196–202.
- Braybrook D, Bristowe K, Timmins L, Roach A, Day E, Clift P, et al. Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations. BMJ Qual Saf. 2023 Feb 1;32(2):109–20.
- Chammas D, Brenner KO, Gamble A, Buxton D, Byrne-Martelli S, Polisso M, et al. Top Ten Tips Palliative Care Clinicians Should Know About the Psychological Aspects of Palliative Care Encounters. Journal of Palliative Medicine. 2024 Feb;27(2):251–4.
- Chu A, Barbera L, Sutradhar R, Oz UE, O'Leary E, Seow H. Association between end-of-life cancer care and immigrant status: a retrospective cohort study in Ontario, Canada. BMJ Open. 2021 May 1;11(6):e042978.
- Chung JE, Karass S, Choi Y, Castillo M, Garcia CA, Shin RD, et al. Top Ten Tips Palliative Care Clinicians Should Know About Caring for Filipino American and Korean American Patients. Journal of Palliative Medicine. 2024 Jan;27(1):104–11.
- Dawe R, Penashue J, Benuen MP, Qupee A, Pike A, Soeren M van, et al. Patshitinikutau Natukunisha Tshishennuat Uitshuau (a place for Elders to spend their last days in life): a qualitative study about Innu perspectives on end-of-life care. BMC Palliative Care. 2024 May 17;23(1).
- Elk R, Emanuel L, Hauser J, Bakitas M, Levkoff S. Developing and Testing the Feasibility of a Culturally Based Tele-Palliative Care Consult Based on the Cultural Values and Preferences of Southern, Rural African American and White Community Members: A Program by and for the Community. Health Equity. 2020 Mar 1;4(1):52–83.
- Fang ML, Sixsmith J, Sinclair S, Horst G. A knowledge synthesis of culturally- and spiritually-sensitive end-of-life care: findings from a scoping review. BMC Geriatrics. 2016 May 18;16(1):107.
- Glyn-Blanco MB, Lucchetti G, Badanta B. How do cultural factors influence the provision of end-of-life care? A narrative review. Applied Nursing Research. 2023 Oct 1;73:151720.
- Grill KB, Wang J, Scott RK, Benator D, D'Angelo LJ, Lyon ME. What Do Adults With HIV Want? End-of-Life Care Goals, Values and Beliefs by Gender, Race, Sexual Orientation. Am J Hosp Palliat Care. 2021 June 1;38(6):610–7.
- Hadler RA, Weeks S, Rosa WE, Choate S, Goldshore M, Julião M, et al. Top Ten Tips Palliative Care Clinicians Should Know About Dignity-Conserving Practice. Journal of Palliative Medicine. 2024 Apr;27(4):537–44.
- Isaacson MJ, Lynch AR. Culturally Relevant Palliative and End-of-Life Care for U.S. Indigenous Populations: An Integrative Review. J Transcult Nurs. 2018 Mar 1;29(2):180–91.
- Jones KF, Laury E, Sanders JJ, Starr LT, Rosa WE, Booker SQ, et al. Top Ten Tips Palliative Care Clinicians Should Know About Delivering Antiracist Care to Black Americans. Journal of Palliative Medicine. 2022 Mar;25(3):479–87
- Kelley ML, Prince H, Nadin S, Brazil K, Crow M, Hanson G, et al. Developing palliative care programs in Indigenous communities using participatory action research: a Canadian application of the public health approach to palliative care. Ann Palliat Med. 2018 Apr;7(Suppl 2):S52–72.
- Kimball J, Hawkins-Taylor C, Anderson A, Anderson DG, Fornehed MLC, Justis P, et al. Top Ten Tips Palliative Clinicians Should Know About Rural Palliative Care in the United States. Journal of Palliative Medicine. 2024 Sept;27(9):1220–8.
- Latif Z, Kontrimas J, Goldhirsch J, Abrahm J, Warraich HJ. Top Ten Tips Palliative Care Clinicians Should Know About Working with Medical Interpreters. Journal of Palliative Medicine. 2022 Sept;25(9):1426–30.

- Lintott L, Beringer R, Do A, Daudt H. A rapid review of end-of-life needs in the LGBTQ+ community and recommendations for clinicians. Palliat Med. 2022 Apr 1;36(4):609–24.
- Madni A, Khan S, Bilbeisi T, Pasli M, Sakaan F, Lahaj SM, et al. Top Ten Tips Palliative Care Clinicians Should Know About Caring for Muslims. Journal of Palliative Medicine. 2022 May;25(5):807–12.
- Monette EM. Cultural Considerations in Palliative Care Provision: A Scoping Review of Canadian Literature. Palliative Medicine Reports. 2021 May 1;2(1):146–56.
- Moore CM, Pan CX, Roseman K, Stephens MM, Bien-Aime C, Morgan AC, et al. Top Ten Tips Palliative Care Clinicians Should Know About Navigating the Needs of Adults with Intellectual Disabilities. Journal of Palliative Medicine. 2022 Dec;25(12):1857–64.
- Patel RV, Patel VR, Patel DR, Kamal AH, Nelson JE.Top Ten Things Palliative Care Clinicians Should Know About Caring for Hindus. Journal of Palliative Medicine. 2020 July;23(7):980–4.
- Phiri GG, Muge-Sugutt J, Porock D. Palliative and End-of-Life Care Access for Immigrants Living in High-income Countries: A Scoping Review. Gerontology and Geriatric Medicine. 2023 Jan 1;9:23337214231213172.
- Quach BI, Qureshi D, Talarico R, Hsu AT,Tanuseputro P. Comparison of End-of-Life Care Between Recent Immigrants and Long-standing Residents in Ontario, Canada. JAMA Netw Open. 2021 Nov 2;4(11):e2132397.
- Roberts NJ, Harvey LA, Poulos RG, Ní Shé É, Dillon Savage I, Rafferty G, et al. Lesbian, gay, bisexual, transgender and gender diverse and queer (LGBTQ) community members' perspectives on palliative care in New South Wales (NSW), Australia. Health & Social Care in the Community. 2022;30(6):e5926–45.
- Rosa WE, Roberts KE, Braybrook D, Harding R, Godwin K, Mahoney C, et al. Palliative and end-of-life care needs, experiences, and preferences of LGBTQ+ individuals with serious illness: A systematic mixed-methods review. Palliat Med. 2023 Apr 1;37(4):460–74.
- Rosa WE, McDarby M, Buller H, Ferrell BR. Communicating with LGBTQ+ persons at end of life: A casebased analysis of interdisciplinary palliative clinician perspectives. Psycho-Oncology. 2023;32(12):1895–904.
- Rosenberg LB, Goodlev ER, Izen RSE, Gelfand SL, Goodlev CL, Lanckton RB, et al. Top Ten Tips Palliative Care Clinicians Should Know About Caring for Jewish Patients. Journal of Palliative Medicine. 2020 Dec;23(12):1658–61.
- Salifu Y, Ekpor E, Bayuo J, Akyirem S, Nkhoma K. Patients' and caregivers' experiences of familial and social support in resource-poor settings: A systematically constructed review and meta-synthesis. Palliat Care. 2025 Oct 1;19:26323524251349840.
- Schuster-Wallace CJ, Nouvet E, Rigby I, Krishnaraj G, Laat S de, Schwartz L, et al. Culturally sensitive palliative care in humanitarian action: Lessons from a critical interpretive synthesis of culture in palliative care literature. Palliative & Supportive Care. 2022 Aug;20(4):582–92.
- Stein GL, Berkman C, O'Mahony S, Godfrey D, Javier NM, Maingi S. Experiences of Lesbian, Gay, Bisexual, and Transgender Patients and Families in Hospice and Palliative Care: Perspectives of the Palliative Care Team. Journal of Palliative Medicine. 2020 June;23(6):817–24.
- Suurmond J, Lanting K, de Voogd X, Oueslati R, Boland G, van den Muijsenbergh M. Twelve tips to teach culturally sensitive palliative care. Medical Teacher. 2021 July;43(7):845–50.
- Tolchin DW, Rushin C, Tolchin B, Slocum C, Meyerson JL, Havercamp SM, et al. Top Ten Tips Palliative Care Clinicians Should Know About Providing Care for People With Disabilities. Journal of Palliative Medicine. 2024 Aug;27(8):1064–73.
- Vincent D, Rice J, Chan J, Grassau P. Provision of comprehensive, culturally competent palliative care in the Qikiqtaaluk region of Nunavut: Health care providers' perspectives. Can Fam Physician. 2019 Apr;65(4):e163–9.
- Wang K, Ma C, Li FM, Truong A, Shariff-Marco S, Chu JN, et al. Patient-reported supportive care needs among Asian American cancer patients. Supportive Care in Cancer. 2022 Nov 1;30(11):9163–71.
- Weisgerber L, Bassah N, Santos Salas A. Indigenous Peoples' Experiences in Palliative and End-of-Life Care in Canada: A Scoping Review. Journal of Advanced Nursing.

uOttawa

ISENBERG LAB

Santé Bruyère Health

QUESTIONS?

isenberglab.com

Case Study: M.L.

Meet M.L.:

- Age: 80
- Gender: Female (she/her)
- Diagnosis: Advanced COPD and metastatic lung cancer
- Lives in Halifax, NS and is supported at home by the Continuing Care Program
- Living situation: M.L. is widowed and lives with a son and daughter-in-law and 2 grandchildren
- Care plan: After repeated hospitalizations, M.L. wishes to remain at home with family
- Care team: – Local home care nurse, continuing care aides through and case manager through the regional health service – Primary care provider (family physician) – Specialist palliative care team through oncology program

Case Study M.L.

Present Situation:

- Several chest infections have contributed to a significant decline in M.L.'s health in recent weeks and it is clear she is nearing end-of-life.
- She has limited energy, breathing difficulties, relies on home oxygen and is almost entirely restricted to bed.
- Her desire to remain at home is influenced by her experiences, culture and values.
- All communication between the care team and M.L. is through her son.
- The family will not speak about death due to beliefs

Case Study M.L.

Care Challenges:

- Communication gaps and differing beliefs about death created tension and the team feels challenged in their ability to deliver a person- and family-centred approach.
- The care team recognizes the impact and influence that language, immigrant experience and cultural attitudes have on the care team/family relationship, however, worry that M.L.'s autonomy is affected by all updates and care discussions go through the son.
- Cultural practices (incense burning) present safety concerns and the reluctance to discuss death limits end-of-life planning.
- The team feels that M.L. could have unmet needs, including physical (pain), cultural and spiritual, particularly when the approach is influenced by local "norms" and services.
    - What steps could be taken to ensure a holistic care plan is in place?
    - What are the obvious barriers the care team has considered ? What are the less obvious barriers and needs that may be missing?

Discussion / Q&A

Dr. Sarina Isenberg, PhD, MA
Chair in Mixed Methods Palliative Care Research,
Bruyère Research Institute
Associate Professor, Department of Medicine,
and School of Epidemiology and Public Health,
University of Ottawa

Dr. Lisa Boucher, PhD
Postdoctoral Fellow
Bruyère Health Research Institute
Faculty of Medicine,
University of Ottawa

Kyle Druillard, MSc, BSc Psych
Research Coordinator
Bruyère Health Research Institute

Upcoming TeleECHO Sessions

CHCA Project ECHO
Integrated Seniors Care
All Teach, All Learn
Bridging the Knowledge Gap in
Home and Primary Health Care

Coordinating Transitions in Complex Dementia and Multimorbidity Cases
November 26, 2025 | 12–1pm ET
Presenter: **Dr. Ivy Oandasan**
Panelists: **TBC**

Strengthening Integrated Care Planning with interRAI-HC and CAPs
December 3, 2025 | 12–1pm ET
Presenter: **Dr. John Hirdes**
Panelist: **Dr. Leslie Eckel,** others TBC

Navigating Autonomy and Safety in Complex Care
December 10, 2025 | 12–1pm ET
Presenter: **Dr. Kerry Bowman**
Panelists: **Olesya Kochetkova, VON**, others TBC

1 Mainpro+® Certified Activity credits for each session

Register: cdnhomecare.ca/chca-project-echo