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ORAL PRESENTATIONS

Misalignment of care needs and provision: Exploring root causes of racial disparities in palliative care

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Background: Racially and ethnically associated disparities in palliative care access and outcomes are well documented. In the pursuit of equitable care, identifying and understanding the underlying root causes of disparities is essential for designing interventions that target problems at the source - yet few studies investigate determinants of disparities.

Alignment between patient care needs and the care they receive is associated with positive health outcomes. Patients who are racially or ethnically minoritized have communication and care needs shaped by their culture, language, historical context and lived experiences, including previous and ongoing racism. However, because health care systems, policies, and practices are historically designed without considering these needs, these patients are at greater risk of receiving poorly aligned care, and therefore poorer outcomes.

Despite its importance, little is known about the driving and mitigating factors of poor alignment between care needs and care provision within a palliative care context, nor the strategies by which to improve this alignment.

Objectives: To synthesize current literature regarding alignment between the care needs of racially and ethnically minoritized patients and the palliative care that they receive, identifying characteristics of 'good alignment' and the conditions that foster it.

Research approach: Following Whittemore et al.'s approach to integrative reviews[1], we searched bibliographic databases for studies that collected race or ethnicity variables in a palliative care context (January 1, 2011 to October 17, 2023), and identified those aiming to understand determinants of disparities[2]. We thematically analyzed the findings for 36 studies to generate themes about communication and care needs and the ways in which organizations and clinicians provide care that aligns with these needs.

Relevance: Sustainable improvements in alignment between palliative care and patient needs may be achieved when strategies are organizationally driven, active, anticipatory, and planned. These strategies should be co-developed with patients and community members and grounded in a shared understanding of needs and meaningful solutions.

Originality: Our findings address a gap in the literature by advancing beyond asking *if* disparities exist in palliative care to understanding *how* determinants of disparities - like alignment - can be effectively targeted for intervention.

Relevance to conference theme: Understanding how alignment drives disparities in palliative care access and outcomes and the opportunities for intervention are essential to providing equitable care.

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Advanced care planning for people with cancer in palliative care in Colombia: Phenomenological approach

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Introduction: Advanced care planning (ACP) is essential for ensuring that the preferences and values of patients with advanced cancer are respected at the end of life. However, significant challenges exist in its implementation, particularly in low- and middle-income countries like Colombia. These challenges include late diagnoses, limited awareness of palliative care, cultural barriers, and difficulties in communication between patients, families, and healthcare providers. Understanding the perspectives of patients in palliative care regarding ACP is crucial for improving its integration into healthcare systems.

Aim: This study aims to explore the experiences and perspectives of patients with advanced cancer regarding ACP in Medellín, Colombia, to identify barriers and facilitators influencing its adoption.

Methods: A qualitative study with a hermeneutic phenomenological approach was conducted. Nine patients with advanced cancer receiving palliative care in a specialized hospital in Medellín participated. Data were collected through in-depth interviews, focusing on their understanding, attitudes, and decisions related to ACP. Thematic analysis was performed using Atlas.Ti software to identify emerging themes.

Results: Six key themes emerged from the analysis: (1) *Clinging to life*: patients expressed a desire to continue treatment despite a poor prognosis, often due to a lack of understanding of palliative care; (2) *Delegation of decisions*: many patients deferred decision-making to family members, healthcare providers, or religious beliefs; (3) *Silence to avoid suffering*: patients and families avoided discussing end-of-life preferences to prevent emotional distress; (4) *Resignation*: a sense of inevitability regarding death emerged when no further treatment options were available; (5) *A quiet place*: patients emphasized the importance of a peaceful environment, free of suffering, whether at home or in a hospital; and (6) *My legacy*: patients sought to leave a lasting impact through teachings, organ donation, or other means.

Conclusions: The study highlights critical barriers to ACP, including a lack of knowledge about palliative care, avoidance of end-of-life discussions, cultural and religious influences, and delegation of decision-making. These findings underscore the need for improved communication strategies, early introduction of ACP, and policies that facilitate meaningful discussions about end-of-life care. Enhancing education for both healthcare providers and patients, integrating ACP into routine care, and addressing cultural concerns are vital steps to ensuring that patients' preferences are honored. The results suggest that fostering a patient-centered approach to ACP can improve the quality of end-of-life experiences for individuals with advanced cancer in palliative care.

Assessment of Clinical Encounters - Communication Tool (ACE-CT): Mixed methods development and validation for use in measuring serious illness communication competence

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Background: To date, assessment for serious illness communication (SIC) competency has primarily used tools that are profession-specific and focused on self-assessments.

Purpose: To address these gaps, we developed and validated a new tool called the Assessment of Clinical Encounters - Communication Tool (ACE-CT).

Research approach: We used a multi-phase mixed methods approach. Phase 1 focused on tool development through a review of existing validated tools, and a Bayesian approach with a national expert panel to assess item quality and item-domain correlation. Phase 2 involved further establishing content validity through think-aloud sessions with panel members. Phase 3 entailed testing the tool, where panel members evaluated simulated patient encounters for practicing interprofessional learners engaging in a SIC education program.

Relevance: In Phase 1, 37 relevant items from previously validated tools were initially pooled. Eleven pooled items were considered redundant and removed, and two new items were generated. Through the Bayesian process, 14 items which had low-to-medium agreement on relevance were also removed. In Phase 2, 2 items were combined into 1, and 2 more items were generated. Items were also further refined for phrasing and order to ensure each was measurable and understandable. For Phase 3, Cronbach's Alpha for the ACE-CT was found to be 0.962. The average measures intraclass correlation coefficient for inter-rater reliability and intra-rater reliability were 0.667 (p-value <0.001) and 0.689 (p-value <0.001) respectively. Pearson correlation between the average ratings for the ACE-CT and a global conversational quality item was 0.937 (p-value: <0.001). Most expert raters agreed that the ACE-CT was easy to complete (77.8%) and that it accurately captured their perceptions regarding the quality of communication (66.7%).

Originality: The ACE-CT serves as a novel tool for objective SIC assessment. Through its interprofessional, person-centred, and competency-based orientation, it addresses a significant gap in assessing clinicians' ability

to communicate meaningfully with patients living with a serious illness (e.g., listening to understand, responding to emotions, and speaking to be understood). Moreover, evidence of reliability and validity across multiple domains, generated through a multi-phase mixed methods approach, positions this tool as a valuable resource across diverse clinical contexts.

Relevance to the conference theme: This study aligns with the conference theme of technology and innovation in palliative care. Communication is the bedrock of effective palliative care and public health practice, serving as the conduit for delivering compassionate care. Through use of the person-centred ACE-CT, future work can evaluate where and when clinicians struggle to communicate with patients (e.g., responding to emotion in the context of oncological settings with migrant populations), as well as how SIC competence affects patient outcomes and experiences. This in turn can help inform the development of new interventions to improve population-level outcomes.

Developing a compassionate university for serious illness, death, and bereavement: Insights from a longitudinal process evaluation

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Background: Compassionate communities are gaining momentum as a new public health approach, emphasizing community support during times of serious illness, death, and bereavement. Death and grief festivals have been planned to offer ‘ways in’ to these topics via participatory, creative, educational, and cultural activities. However, evidence on the development and sustainability of compassionate communities and these specific community engagement initiatives remains limited, particularly within higher education.

Objectives: This study investigates the development of a Compassionate University, examining the underlying processes and contextual factors shaping its development. Additionally, it presents insights from a concrete initiative, the *Compassionate Week,* organized at the university to cultivate awareness and encourage open dialogue about serious illness, death, and bereavement.

Research approach: A longitudinal process evaluation was conducted, using field notes, right-now surveys, individual interviews, focus groups, and strategic learning debriefs. Two implementation frameworks, the Consolidated Framework for Implementation Research (CFIR) and the Normalization Process Theory (NPT), guided the process of data collection and analysis. Moreover, 94 semi-structured interviews were conducted with participants of the Compassionate Week to capture their motivations and experiences with the activities they attended.

Relevance: Despite the growing development of compassionate community initiatives, rigorous systematic understanding, scientific description, and evaluation of their development, implementation, and underlying mechanisms remain a challenge. This leaves unanswered questions about their practical implementation, contextual nuances, and factors driving or hindering their success.

Originality: This study contributes to the field of Public Health and Palliative Care by demonstrating the potential for educational institutions to function as compassionate schools and workplaces. It also enriches the research field by emphasizing the value of non-traditional, qualitative, and participatory research designs in evaluating these initiatives, paving the way for deeper understanding of systemic and community-driven change. Moreover, the presentation explores the barriers and opportunities encountered in co-developing a community initiative with students and staff, inviting discussion on ‘meaningful’ community engagement and sustainability.

Relevance to conference theme: The study aligns with the conference’s theme, “Innovating Care: Research and Action for Public Health and Palliative Care,” by studying a pioneering initiative, the development of a Compassionate University. Using implementation frameworks and qualitative methods, this research provides a deeper understanding of how such initiatives can be (co-)designed, (co-)implemented, and evaluated.

The study was funded by the Compassionate Communities Centre of Expertise (COCO).

Evaluating the unknown: Navigating the evaluation of hospice-based public health palliative care activities

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Background: Evaluation methodologies historically grounded in western research traditions - or reliant on quantitative outcome measures - are challenging to apply in the evaluation of community-led initiatives. *Creating Compassionate Communities,* a three-year community engagement initiative within a hospice, has required an innovative and culturally responsive evaluation approach to honour diverse worldviews and community driven approaches.

Objectives: To critically examine the methodological challenges of evaluating co-designed community initiatives within a hospice setting, and to develop alternative approaches that better capture the complexity of Public Health Palliative Care initiatives.

Research approach: We employed a "bricolage" (mixed-methods) evaluation methodology, inspired by frameworks that weave together Indigenous knowledge (mātauranga Māori) with western evaluation approaches. Data sources included team member reflections, partner feedback, participation metrics, and ongoing process documentation. The evaluation framework was iteratively adapted to respect data sovereignty and community ownership of co-designed initiatives.

Relevance: This work addresses what we perceive as a critical gap in evaluation methodology. Our findings highlight the importance of developing flexible approaches that accommodate emergent outcomes, honor diverse worldviews, and support genuine community partnership within community engagement initiatives.

Originality: Our evaluation experience provides novel insights into measuring the impact of community engagement in palliative care, whilst respecting Indigenous knowledge systems and community-led processes.

Relevance to conference theme: This work directly addresses innovation in palliative care research by developing approaches to evaluation that center equity, community voice, and cultural safety.

Measuring the effectiveness of a Compassionate Communities initiative to raise public awareness of palliative care and advance care planning: An evaluation framework

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Background: Raising awareness of palliative care and advance care planning is essential to better prepare people for living with serious illness, dying, caregiving and grieving. We undertook a multi-year, multi-sectoral Compassionate Communities initiative (2020-2025) to increase public awareness and understanding of palliative care and advance care planning. Public education tools were adapted to our local context and implemented in collaboration with community partners.

Objectives: To develop an evaluation framework for: 1) determining program effectiveness in raising public awareness of palliative care and advance care planning, and 2) contributing to best practice and knowledge on evaluating Compassionate Communities public awareness initiatives.

Research approach: We began by reviewing the literature to identify relevant framework(s) to guide our evaluation. Key informant interviews were held with stakeholders to solicit feedback on the selected evaluation framework(s) and proposed measures. A logic model was developed to synthesize the goals, inputs, audience, activities, and anticipated outputs of the public awareness initiative. Data collection is ongoing until September 2025.

Relevance: This presentation will describe how we adapted the Healthy End of Life Program (HELP) Evaluation Framework and the Australia Palliative Care Evaluation framework to guide our process and outcome evaluation, respectively. We chose to adapt the HELP framework based on its public health palliative care approach to evaluation, health promotion principles, and focus on community development. We adapted the Australia Palliative Care Evaluation framework to capture impacts on 'consumers', 'providers', and the 'broader care delivery system'. Outcome measures were adopted or adapted from validated tools where available and appropriate; new measures were developed to assess domains lacking validated tools. Our process measures indicate we have created change in six of the eight HELP domains (People, Programs, Participation, Practice & Practitioners, Place, Partnerships); outcome data collection suggests our tools are improving knowledge of and attitudes toward palliative care and advance care planning.

Originality: The evaluation of Compassionate Communities initiatives is a relatively new area of study, with no consensus on best approaches to measurement. We have successfully adapted evaluation frameworks for comprehensive evaluation of a Compassionate Communities initiative, and this approach may prove useful for similar public awareness programs.

Relevance to conference theme: Our evaluation framework is an innovation in measuring the effectiveness of Compassionate Communities initiatives. Recognizing that communities provide the majority of care for people living with serious illness, our evaluation framework uses a public health approach by measuring change across a number of community development action areas.

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Supporting the Journey Home: Community-based palliative care education with health care providers in First Nations communities

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Background: Healthcare providers (HCPs) working in First Nations (FN) communities are knowledgeable and resourceful and understand their community's strengths and unique challenges. This includes the challenges with accessing home-based care and local palliative care services. This often results in FN people who are seriously ill receiving care outside their community. Supporting the Journey Home: Growing the Community Bundle to Care for Those with Serious Illness (SJH) was co-designed with 12 interdisciplinary HCPs working in FN communities across Ontario. The co-design process ensured SJH was a culturally relevant palliative care education program for HCPs providing care in FN communities.

Objectives: SJH provides HCPs working in FN communities with practical resources and tools to operationalize a culturally appropriate early palliative care approach. This presentation will provide a high-level overview of the SJH program and highlight the participants' learning experiences and impacts from the three modules on early identification, communication skills, and strengthening connections among community helpers.

Research approach: To understand participants' learning experiences, we conducted in-depth qualitative interviews with 19 HCPs who completed SJH. We followed a qualitative descriptive design and completed a thematic analysis of interview data.

Relevance: This research project aims to assess the learning experiences, cultural appropriateness, and utility of SJH in instilling an early palliative approach to care from the perspective of program participants. Findings from our evaluation indicate that SJH helped shift their thinking from end-of-life care to an early palliative care approach and increased their confidence in initiating this care. Participants also shared the impact of learning through hearing stories from the co-facilitators who are HCPs working in FN communities.

Originality: In Ontario, Canada, several training programs work to improve home-based palliative care, focusing on meeting needs specifically at end-of-life. Education on incorporating an early palliative care approach from a FN perspective is necessary to complement these existing education programs. SJH complements and enhances these existing educational programs by emphasizing the importance of an early palliative approach to care, not just at the end of life, in a way that is culturally relevant, wholistic, and honours FN values and culture.

Relevance to conference theme: This project emphasizes the importance of culturally sensitive palliative care practices by promoting the involvement of HCPs who work in/with FN communities in designing and implementing the SJH palliative care education program. This presentation will benefit all HCPs in recognizing the benefits and impact of Indigenous-led, designed, and implemented palliative care education that instills the importance of an early palliative approach to care.

Funding: First Nations & Inuit Health Branch, Ontario region of Indigenous Services Canada, Government of Canada

Experiences of stigma and opioid prescribing for people with opioid use disorder requiring palliative care: A multi-setting qualitative study

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Background: People with opioid use disorder (OUD) face structural barriers and stigma when accessing opioids in healthcare settings, yet little is known about opioid prescribing in palliative care for people with OUD.

Objective: Explore stigma and opioid prescribing in palliative care among people with OUD in Canada.

Approach: We conducted semi-structured interviews with patients with OUD and life-limiting illness, or their caregivers, and focus groups with healthcare providers who provided palliative care to these patients. We analyzed interviews for themes based in stigma theory using applied thematic analysis, refining the codebook through consensus coding.

Relevance: This study provides insights on the current state of palliative care for people with OUD, including how stigma affects opioid prescribing and care, and identifies ways to improve palliative care accessibility.

Originality: Results suggest that stigma and opioid prescribing are mutually affected and reinforcing. Palliative care specialists do not use standard criteria to identify OUD, and labels in patient charts can encourage stigma. Providers employ a range of strategies to manage opioid risks and often struggle with prescribing high doses for patients with OUD, resulting in inadequate symptom management. Community-based providers are more comfortable than hospital-based providers prescribing higher doses and supporting patients' preferred routes of administration. Patients with OUD experience structural, interpersonal and internalized stigma when seeking care for serious illness, contributing to their avoidance of care.

Relevance to conference theme: Stigma is a social determinant of health that impedes access to palliative care for people with OUD. People with OUD are more likely to be low-income, unhoused, and experience long-term marginalization, further complicating access to palliative care that meets their needs.

Funding: Canadian Institutes of Health Research and Health Canada.

Bot attack! Bots, artificial intelligence, and bereavement research

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Background: In their lifetime, every person will experience the loss of someone they care about. The pandemic, opioid crisis, and confirmation of unmarked graves at residential schools have brought this into particular focus. Yet, there are few accurate statistics about the number of people grieving and how they are being supported. Grief remains stigmatized and relatively hidden (Macdonald, 2019). Our team obtained CIHR funding for the Grief in Canada project, a mixed-methods project to advance public health understandings of grief and its support by testing the Public Health Model of Bereavement Support (Aoun et al., 2015) in the Canadian context, and 2) build a grounded theory of grief support.
Objectives/purpose: During the recruitment phase for our online survey, we were stymied by bot attacks. This presentation will focus on the strategies for prevention and the challenges of managing the increase of AI and bots.
Research approach: Anticipating the changing context of AI, our recruitment and survey were carefully designed to deter bots. We began data collection in May of 2024 and were halted in July because of serious bot attacks. The project has been delayed as a result. Standard checks in place had not been sufficient in preventing bots. Many answers originally determined to be human, were later discovered to be bots, with text box filled in with artificially generated answers, as well as other questions being factually incompatible. Substantial recruitment remuneration has been sent to erroneous 'participants' which has resulted in a waste of time, has budget implications and caused much researcher frustration.
Relevance: This presentation has implications for future of palliative and bereavement survey research. As AI continues to progress, the existence of bots becomes an undeniable part of research. Survey data influences the implications of a study, shaping future research and field work. False survey data compromises the quality of data, potentially shaping future work in inaccurate directions.
Originality: This challenge sits at a cross-roads of research ethics and design. We need to advance this discussion to ensure the continued rigour of palliative care research.
Relevance to conference theme: The implications of this are important to technology and innovation as it crucial for palliative care research to stay up to date with technology and the challenges that come with it.

How do we know what we don't know: Journey mapping to describe palliative and end-of-life care needs for urban Inuit

Valerie Fiset[1], Janet Jull[2], Benjamin Carroll[3], Improving Palliative Approaches to Care for Urban Inuit (IPACUI) project community collaborative partners[4]

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Purpose: This presentation describes the study protocol for the Improving Palliative Approaches to Care for Urban Inuit project (IPACUI), a community-partnered initiative between palliative care and health researchers, Inuit-run and Inuit-serving community and health organizations and urban Inuit experiencing or at risk of homelessness or similar structural vulnerabilities. The project goal is to improve a palliative approach to the care of urban Inuit in Ottawa living with any progressive chronic or terminal illness, including frailty.
Context of the project: Inuit experience disproportionate health burdens and mortalities. For example, Inuit have the highest cancer mortality rates from lung cancers in the world with increasing rates of other cancers. Inuit must often negotiate complex and sometimes unwelcoming health care systems. Project community partners often witness Inuit without means to access care, financial aid for transportation, and/or family or caregivers to accompany them to appointments and to help navigate the medical system.
Research approach: Guided by the Collaborative Research Framework (1), journey mapping will be used to explore the experiences of urban Inuit experiencing the need for a palliative approach or end of life care, as well as those of service providers caring for this community. This process will identify the needs, gaps, supports and challenges in access to culturally safe palliative and end of life care for Inuit in Ottawa.
Relevance & originality: Anecdotally, community organizations that work with Inuit who come to Ottawa for health care report that it is common for people not to return home to their community. They leave the familial and community structural supports (e.g., food, transport, housing) to fend for themselves to meet these needs in tandem with the health crisis that brought them south. Many Inuit in this situation are either at risk of or experience homelessness and structural vulnerability. Other organizations

that support Inuit receiving medical treatment report that many die in hospital or short-term housing without access to culturally appropriate end-of-life care. There are no statistics documenting the prevalence of these issues.

Relevance: Conference themes: This research addresses a significant gap in the knowledge about the social determinants of health and culturally safer palliative approaches to practice for urban Inuit, particularly those facing structural vulnerabilities such as homelessness.

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The intersections of palliative care and homelessness in Canadian social policy

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Background: The physical and emotional toll of homelessness on older adults results in increased rates of chronic illness, earlier onset of frailty, and decreased life-expectancies. The resulting palliative needs are generally not well met by current palliative service provision. As such, palliative care for this population is an important social issue for policy makers.

Policymakers can respond to these challenges by naming the issue in policy documents, allocating resources, and creating frameworks or guiding principles to inform action. While policy plays a crucial role in addressing this issue, the extent to which palliative care and homelessness are discussed in social policy is currently unknown, and we are not aware of any other analyses of this kind.

Objectives: Conduct a policy document analysis to examine how, if at all, policymakers in Canada are identifying and addressing the issue of palliative care for people experiencing homelessness through its inclusion in policies governing palliative care and/or homelessness.

Research approach: Content analysis of Canadian policy documents governing palliative care or homelessness. We analyzed policy documents based on geographic scope; and presence, level and type of content referencing homelessness and end-of life.

Findings & Relevance: The Canadian policy documents analysed rarely discuss the intersections of homelessness and palliative care. Of 75 documents, 42 contained no discussion of palliative care and homelessness, 13 addressed the issue indirectly (through broader concepts of social or health equity), 14 named the issue minimally without further elaboration, and only 6 documents discussed palliative care and homelessness significantly. Our analysis found differences within the level of discussion between the policy documents in the two sectors, with palliative care policy documents more frequently discussing the issue and the only documents to discuss the issue significantly. There were also differences in the content of discussion between the two sectors; bereavement and increased risk of homelessness following spousal death were discussed in homelessness documents but absent from palliative care documents. Conversely, calls to action were included in palliative care documents but missing from homelessness documents. Despite these gaps, the results suggest opportunities for increased collaboration, particularly pertaining to practices to address the end-of-life care needs of homeless older adults. The findings demonstrate the need for increased attention by Canadian policymakers to address palliative care for OPEH, as well as the potential areas ready for collaboration.

Funding: This research has been funded by a CIHR Health System Impact Fellowship.

Equity in cancer care as an upstream public health approach to palliative care: Findings from a qualitative study

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Background: People experiencing structural marginalization often have higher cancer-related mortality and advanced cancer diagnoses resulting from lack access to cancer care. Often, we see people in palliative care who have cancers that would have been amenable to treatment had they had upstream access to cancer care. A key pathway to addressing this gap and improving access to care includes integrating equity-oriented approaches to cancer care (EOCC). EOCC is an approach to care that is person-centered and seeks to reduce the impacts of structural inequities (e.g., poverty, systemic racism). Organizations who take an equity-oriented approach can help address access, quality of life and care gaps.

Purpose: To examine organizational facilitators of equity-oriented cancer care (EOCC).

Originality: Despite growing interest in EOCC, little is known about the organizational factors required to support the delivery of EOCC.

Approach: As an upstream public health approach, our study examined how organizations can improve equity.

Informed by social justice and intersectional perspectives, the study drew on critical ethnographic methods and employed a participatory and integrated knowledge translation approach. We conducted semi-structured interviews with health and social service providers and key informants, observations of oncology settings, and interviews and focus groups with people experiencing structural marginalization, in collaboration with a community partner. Our findings point to three dynamic and intertwined dimensions within organizations delivering cancer services that support an equity-oriented approach to care: integrating core values to create an equity-oriented culture (e.g. relationality, adaptability), building a shared commitment toward EOCC, and taking action towards EOCC.

Relevance: Our findings provide direction for integrating an equity-oriented approach at the organizational level, which creates the organizational context for clinicians to provide tailored, person-centred, and culturally safe-r care.

Relevance to conference theme: This study explicitly focused on advancing equitable access to care across the cancer continuum, with a strong focus on intersectional social determinants of health.

Developing an evaluation framework for government-initiated palliative care reforms: A Theory of Change approach

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Background: Global projections indicate an 87% increase in deaths associated with health-related suffering by 2060, compared to 2016. This projection underscores the growing need for both generalist and specialized palliative care. In response, the Flemish Department of Care launched a reform to integrate palliative care into primary care more effectively, aiming to ensure accessibility for all populations, including those underserved by the current system.

Objective: To develop an evaluation framework to assess the palliative care reform in Flanders.

Research approach: The development of the evaluation framework was guided by the Rainbow Framework for Better Evaluation. This process involved defining evaluation priorities based on a Theory of Change model which was participatory developed with stakeholders, selecting and operationalizing key outcome measures, and constructing a data matrix to identify suitable scientific evaluation methods. The resulting framework integrates outcome monitoring (i.e., a VOICES survey for relatives, a death literacy survey for the Flemish population, logbook measurements from palliative networks, and a Most Significant Change data collection), process monitoring (i.e., interviews with relatives, interviews with key palliative care stakeholders and observations from relevant meetings), and contribution analysis to understand what the decisive factors were in the success or failure of the reform's desired changes.

Relevance & originality: The reform demonstrates how rigorous evidence-based evaluation can enable informed policy adjustments and ensure effective implementation, enabling palliative care for all populations, including those currently underserved. The study's insights extend beyond the Flemish context, offering a transferable framework for evaluating and guiding complex reforms in other contexts, making it a valuable contribution to both palliative care and broader program evaluation research.

A scoping review of literacy concepts and measures related to palliative and end-of-life care, dying and death and grief

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Background: Health literacy is a key social determinant of health and well-being. Poor health literacy is associated with multiple inequities in serious illness, dying, death and grieving, poor access to palliative care, difficulties in health communication, advance care planning, treatment decision-making, and recognising and managing symptoms.

Newer conceptions of literacy have emerged which reflect the range of knowledge, skills and abilities that people draw upon during the palliative and end-of-life care phase, when managing death arrangements and supporting their own and others' grief. 'Palliative care literacy' and 'end-of-life health literacy' (in healthcare settings), 'death literacy' and 'grief literacy' (in home and community settings) are some examples of these.

Objectives: To describe the range of knowledge, skills and abilities included across literacy concepts and measures applied to palliative and end-of-life care, death and grief and to identify conceptual gaps and overlaps in these literacies.

Research approach: A scoping review of published papers that explicitly describe literacy concepts to applied to palliative care, end-of-life care, dying, death and grief.

Relevance: A typology of literacies which reflect the knowledge, skills and abilities needed from initiation of a palliative care/end-of-life approach, through death and into grief is presented. This typology will inform the design of public health interventions to promote literacies to improve equity in experiences and outcomes at these times.

Originality: The findings provide an original contribution to knowledge about death, dying, grieving and palliative care by providing a comprehensive overview of knowledge, skills and abilities that are essential for communities and at a population level to respond to these universal events.
Relevance to the conference theme: The review highlights literacies as a key social determinant of health and well-being and access to informal and formal support.

Identifying palliative care needs in individuals experiencing homelessness by third sector and social professionals. Preliminary results of a qualitative study

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People experiencing homelessness have complex health needs, shortened life expectancy and limited access to palliative care. Identifying palliative care (PC) needs is challenging, due to erratic illness trajectories, lack of continuity and other barriers to access to healthcare. Third sector and social support workers (SSWs) play a key role in recognising health decline and PC needs, but there is limited knowledge about what triggers their worries and their specific strategies to identify who might benefit from a PC approach. This study aims to examine the strategies and indicators used by SSWs, and challenges they face identifying PC needs among individuals experiencing homelessness. Understanding their approach and difficulties might inform the development of tailored tools and enhance multiagency collaboration to ensure timely PC access.

A qualitative study with an interpretive description approach is being conducted, involving thematic analysis of semi-structured interviews and focus groups with professionals from both the public social care system and third sector working with homeless individuals in Bilbao (Spain). This work presents preliminary results focusing on identification strategies, challenges and indicators of PC needs as recognized by SSWs in diverse settings.

Professionals identify PC needs through various indicators of progressive deterioration. Some are similar to those typically detected by healthcare professionals, such as reduced food intake, repeated hospital admissions, frequent falls, and visible signs of illness. But they often detect other affective or relational signs, such as sadness, emotional flattering, isolation, changes in routines and interactions, and increased risk-taking behaviours which often alert a shift from survival to surrender that demands a change in care goals.

SSW provide information to, and receive and integrate alerts detected by homeless individuals, healthcare professionals, family, peers and others. However, several challenges impede timely identification, including limited continuity of care and insufficient time for individualized follow-up. Confounders as unpredictable health trajectories, with paradoxal robustness, and mental health and substance use issues also challenge early identification. Many clients minimize or deny their health status, avoiding medical services due to fear, stigma, or the need for temporary abstinence. Lack of information sharing among health and social systems further complicates identification. Additionally, professionals fear that labelling individuals as palliative may increase stigma.

To address these barriers, professionals rely on routine observation, monitoring behavioural and physical changes, team meetings, and collaboration with healthcare services. Despite these efforts, identifying PC needs remains complex, requiring structural and systemic changes. Co-creating identification tools, strengthening multilevel networks and sharing knowledge between social and healthcare systems would help to ensure appropriate and timely care access.
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Note: This text was refined using AI to improve readability and ensure linguistic accuracy.

A community-based participatory research partnership to strengthen caregiver support in the community

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Context: Informal caregivers play a pivotal role when caring for someone during end-of-life care at home. High physical, emotional, and economic stakes compromise caregivers' wellbeing, but also put patients at risk for unplanned emergency room visits and hospitalization. Community-based palliative care services hold unique potential to support caregivers when caring for someone during end-of-life at home. However, often these services are incomplete and a glaring lack remains regarding which services are most valuable to caregivers accompanying a person dying at home.
Purpose: Here we propose a community-based participatory research project to identify and implement services that support caregivers during end-of-life at home.

Research approach: Applying principles of community-based participatory research, we partnered with caregivers to form a community advisory board. The community advisory board is implicated in all steps of the research process. The advisory board's lived experience as caregivers has supported the conception of this research project. We have met bimonthly to identify our research question, research methodology, and recruitment strategy. To identify key elements that positively support caregivers when providing end-of-life care at home, we employ a solutions-based Appreciative Inquiry approach using individual interviews and focus groups with bereaved caregivers. Identified key elements will then focus in digital storytelling videos to be shared with healthcare teams and stakeholders in our community. In a deliberative dialogue we plan to collaboratively design a healthcare intervention to better support caregivers in the community.

Relevance: We propose to bring the voices of caregivers to the forefront by applying a participatory research process to identify key elements supporting caregivers in their role. Knowledge generated with caregivers will propel a change in clinical practice of community palliative care teams by implementing healthcare services specifically tailored to caregivers' needs.

Originality: Few initiatives for improving the support for caregivers are being conceived with and by those meant to benefit from them. Here we propose a partnership with caregivers to share their knowledge and needs to conceive a healthcare intervention acceptable to caregivers and feasible to implement from a healthcare system perspective.

Relevance to the conference theme: Community palliative care is a public healthcare solution to reduce suffering in patients with serious illness and their caregivers. This research provides an example of how community participation can be harnessed to strengthen these services by generating knowledge on caregivers needs and proposing action to address these needs. Thereby, patients with serious illness and their caregivers can receive the support they deserve in their communities.

Rethinking early palliative care: Understanding Its real-world impact on survival in advanced non-small cell lung cancer

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Background: Patients with advanced non-small cell lung cancer (NSCLC) face a high symptom burden and poor prognosis. While previous studies suggest early palliative care (EPC) improves quality of life, reduces symptom burden and hospital use, and extends survival for advanced NSCLC patients, there is limited evidence on the real-world impact of EPC on survival for these patients.

Objective: This study investigated the association between EPC at the time of advanced NSCLC diagnosis and overall survival, accounting for patient-reported symptom burden.

Research approach: We conducted a retrospective, population-based cohort study using ICES data. Patients receiving palliative intent anticancer treatment and who had a symptom burden score within 8 weeks of diagnosis were included. EPC was defined by receipt of specialist palliative care consultation within 8 weeks of first palliative intent anticancer treatment. Baseline characteristics were summarized, and patients were stratified by symptom burden (low, moderate, high). Propensity score matching was used to compare those who received EPC with those who received late palliative care or no palliative care. Kaplan-Meier curves and multivariate Cox regression were applied to evaluate the impact of EPC on survival.

Results: A total of 1,720 patients were matched on baseline characteristics. Contrary to our hypothesis, those who received EPC had lower survival within the first 4 years. Survival rates were 21.74% vs. 40.58% at 1 year, 8.88% vs. 21.71% at 3 years, and 4.13% vs. 10.41% at 4 years ($P < .001$). Multivariable Cox regression showed EPC was associated with decreased survival (HR: 1.59, 95% CI 1.48-1.71), consistent across symptom burden groups. Poisson regression analyses revealed that patients with worse patient-reported functional status and symptom burden were more likely to receive EPC. Receipt of EPC also varied based on year of diagnosis, region, rurality, type of first palliative intent anticancer treatment, and number of emergency department visits.

Relevance: Patients receiving EPC had worse survival, likely because EPC was prioritized for those nearing end of life, suggesting it was responsive rather than proactive EPC. This highlights the need for timely integration of EPC to maximize its potential benefit on both quality of life and survival in advanced NSCLC patients.

Originality: This study informs clinical practice in Ontario by demonstrating symptom-based integration of early palliative care (EPC) among people with advanced NSCLC is needed. It has policy relevance by highlighting regional and systemic disparities in EPC access and contributes methodologically by integrating patient-reported symptom burden into population health research, offering a model for more precise measurement of healthcare interventions.

Providing palliative care navigation to refugees claimants in the Greater Toronto and Hamilton Area (GTHA): An innovative approach to equitable access to palliative care

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Background: *The Framework on Palliative Care* stipulates palliative care (PC) as an essential service. Unfortunately, PC is restricted for marginalized populations, including refugees. Refugee claimants are only eligible for the Interim Federal Health Plan (IFHP), which provides basic medical and social coverage until provincial healthcare coverage begins. While IFHP provides some home-based palliative support, it is restrictive and inaccessible due to significant administrative burdens. A paucity of data on the experiences of refugees in Canada requiring PC remains.
Objectives: This presentation will highlight barriers and facilitators in providing PC to refugees in the Greater Toronto and Hamilton Area (GTHA) of Ontario from the perspective of healthcare professionals (HCPs), allowing audience members to gain a better understanding of regulatory, financial, and administrative environments. It will also highlight the resultant intervention designed to address the gaps in care and the early challenges and successes of the intervention.
Methods: Following a mixed-methods approach, local administrative data from two sites in the GTHA (2017-2023) were collected to review healthcare utilization patterns for refugee claimants with PC needs. Fourteen HCPs from both sites participated in focus groups to better understand care management experiences. Using study results, an intervention, "GPS Health Navigators," was launched in in January 2024 to help mitigate inequitable care gaps. A pilot project is currently underway to evaluate the service and patient/caregiver experiences to help identify early successes and challenges of the intervention.
Results: With significant barriers to accessing community PC, refugee patients with PC needs appeared to access acute care services more often (with an average of 2.43 [SD 2.23] hospitalizations and 7.05 ER visits [11.27] over a five-year period) to manage care needs. Furthermore, HCPs' experiences highlighted challenges for coordinating home supports, given restricted access to home-care, creating a reliance on acute care and/or increased out-of-pocket costs for patients. Since the launch of GPS Health Navigators, we have successfully serviced refugee patients with PC needs. A pilot project assessing the impact of the intervention has yielded early successes, including the development of administrative processes for providing timely home-care, and increasing the ability for our clients to die in their preferred setting (including at home and hospice). Early challenges include fluctuating human resources and finding reliable and consistent care providers.
Conclusion: This study highlights significant gaps in PC access for refugees on IFHP leading to possible over-reliance on acute care to meet basic palliative care needs. Our intervention aims to address a significant gap in PC access for refugees through the creation of a unique and innovative community-based navigation service. Equitable access through compassionate and dedicated healthcare navigation is essential in ensuring that quality PC is available to all.
Funding: Pan-Canadian Palliative Care Research Collaborative Seed Grant and Healthcare Excellence Canada.

I welcome the conversation: What talking to people about Assisted Dying helps us understand about community priorities

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Background/context of the study/work: Recent calls to legalise Assisted Dying in the UK have provoked a surge of interest in international models and context, and in conversations about dying and palliative care. Meanwhile, the media depiction of viewpoints on assisted dying present a nation potentially at loggerheads - or as it relates to death, fearful of speaking. Is this the case? Likewise, little visibility of public viewpoints and perspectives on death and loss remain a gap in our knowledge and prioritisation of end of life support, which exacerbate inequalities.
Objectives/purpose: This paper uses the idea of talking to members of the public about assisted dying to provide a focal point on the importance of working with community members to create priorities for end of life care and support. It follows and shares the work of a community action team working in South London and holding and hosting conversations about subjects relevant to end of life. It asks, what are people concerned about, and have we got our priorities for conversation right?
Research approach: The Community Action Team has worked over 5 years to advance a participatory and community-development approach to hold important conversations about end of life with people living locally. It divides work into community learning, support, co-production and development and seeks to understand community concerns.

Community conversations about assisted dying used qualitative and dialogue-based methods including peer groups and 1-1 conversations, as well as participatory policy discussion. Performance and talks were also used to support people to consider ideas about death, dying and support. Conversations were considered by a wide group of stakeholders and original participants were invited to comment on the meaning and relevance, including a wider group of healthcare professionals.

Relevance: The study should advance knowledge and institutional practice as it reveals community priorities to often be different from institutional preoccupations, and at other time reveals a high level of policy and inequalities literacy amongst populations. The subject of policy acts as a conduit for preoccupations and concerns around how we support one another, trust in institutions, and is a commentary on our shared interest in tackling inequalities.

Originality: Assisted Dying is much studied, but the subject in this setting and with the people involved sheds more or new light on how communities would prioritise our response to death that offer some different insights into it, especially within the context of inequalities and policy.

Relevance to conference theme: The conference focuses on community and health inequities. The paper asks if communities are concerned about the same things healthcare institutions are and emphasises the importance of working collaboratively with communities to explore change.

Challenging norms at the end-of-life through LGBTQ+ perspectives

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Background: Sexual and gender minority populations (LGBTQ+) have historically been structurally marginalized through criminalization and pathologization. Marginalization continues through current societal movements limiting LGBTQ+ rights and questioning LGBTQ+ identities. Research finds that structural marginalization may affect LGBTQ+ people's experiences and concerns regarding dying, death, loss and care at the EoL. However, pertinent knowledge gaps exist in public health and palliative care as research often reproduces prevailing heteronormative perspectives.

Objectives: To use Kastenbaum's Death System concept as a theoretical lens to explore experiences around dying, death, loss, and EoL-care from the perspectives of LGBTQ+ people in Sweden.

Research approach: In this qualitative interview study, participants were recruited through DöBra Rainbow Cafés, i.e., meeting places for and by LGBTQ+ people to engage with EoL-issues held in partnership between researchers and LGBTQ+ organizations. Thirty-one interviews were held (participants' age 25-88). Kastenbaum's death system theory was used as a basis for analysis. The theory describes how societies structure and handle processes related to dying, death, and bereavement. It describes that death systems can be analyzed through its functions (such as preventing death and caring for the dying) and components (such as people, places, times, and objects) that interact to shape societal responses to death. Interviews are analyzed through these functions and components.

Relevance: Research findings provide insights into ways in which the death system in the Swedish society perpetuates heteronormative perspectives which in turn causes clashes with the needs and social contexts of LGBTQ+ people. Findings indicate a resilience, creativity, and resourcefulness in ways in which participants dealt with such clashes, which we described as "queering the death system". However, findings also point out opportunities for care and policy to challenge and transform heteronormative practices to be inclusive of the experiences, needs, and contexts of LGBTQ+ people. Findings are relevant as LGBTQ+ people face structural marginalization globally, and norms related to gender and sexuality likely affect death systems in many societies.

Originality: This research addresses pertinent knowledge gaps regarding LGBTQ+ needs at the end-of-life. It further contributes with a novel application of Kastenbaum's Death System concept, encouraging further use in public health and palliative care. Furthermore, findings can be applied in public health and palliative care policy and practice.

Relevance to the conference theme: This research is relevant to the conference theme as it points out ways in which the death system can innovate to be more equitable for LGBTQ+ people. Furthermore, drawing on these findings as well as on research with other structurally marginalized and underserved people, we argue that death systems should be transformed to include anyone living outside the norm.

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End-of-life through the lens of Life Span Development: Meeting common social-emotional needs

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Background: The lifespan development framework views development as a lifelong process. As life expectancy increases, a phase near the end of life, marked by health challenges, becomes a common part of the life course. Despite notable progress in palliative care, the emotional

and relational dimensions remain challenging—due to the tendency to reduce complex experiences to binary oppositions (such as dependence versus independence) or fragment them into isolated concepts, making the underlying processes and mechanisms harder to understand. Greater effort is needed to advance integrated perspectives that address fundamental needs and motivations throughout the end-of-life experience. Grounding public health initiatives in these basic end-of-life intentions could enhance their relevance, applicability, and overall effectiveness.
Aim: To explore the motivations behind the experiences of individuals nearing the end of life.
Methods: A critical realist grounded theory approach was applied to analyze open-ended responses from 99 dying patients (mean age 76), gathered at two time points, and 32 in-depth interviews with 16 patients (mean age 66).
Results: We defined the end-of-life process as a multidimensional continuum of agency—returning, persisting, and coming to terms. It reflects patterns shaped by intentions and emotions, changing anticipations, and shifting time perspectives—all of which are embodied and relational, and therefore closely connected to processes of decline, recovery, and the surrounding social context.

- **Returning** refers to efforts to improve one's condition and regain a previous state or level of functioning, often by focusing on manageable tasks, short-term improvements, and avoiding thoughts of further decline.
- **Persisting** involves maintaining health and daily functioning while navigating the tension between autonomy and the need for relational security. It holds space for the possibility of both recovery and decline, in the absence of immediate crisis.
- **Coming-to-terms** involves recognizing one's vulnerability to illness and decline. When decline is anticipated or understood as irreversible, attention often shifts toward safety, comfort, and the presence of caregivers.

Common emotionally-driven intentions—such as avoiding suffering and managing fear, maintaining agency, giving and receiving care—shaped behavior, were forward-oriented, and were met in relationships. Yet, emotional-relational needs were frequently overlooked in patient care.
Conclusions: Common intentions at the end of life reflect basic emotional needs—such as reducing anxiety by preparing for expected challenges, maintaining a sense of agency despite increasing dependency with support from others, and having an attentive caregiver nearby. These needs are often downplayed or implicit in care compared to immediate physical concerns. Aligning end-of-life care with process dimension and intentions, within the context of one's environment, can improve well-being and reinforce the developmental continuum from early life to its final stage. Agency and intention bridge the individual and their social context. Understanding such processes and intentions allows for more effective, personalized, and equitable care.

Understanding bereavement in the context of homelessness from those with a lived experience

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Background: Those experiencing both bereavement and homelessness are commonly unrecognized grievers and inadequately supported in their bereavement. There has been little research in this area, which limits our understanding and ability to improve bereavement support for them. Recent research in BC explored community support workers' perspectives on the topic, but research is still needed with those who have lived experience of bereavement and homelessness.
Objective: This project aimed to better understand the bereavement experiences of those who experiencing homelessness and their thoughts on how to provide better bereavement support.
Methods: We conducted 80 in-person interviews with people with lived experience of bereavement in the context of homelessness in Kelowna and Vancouver, British Columbia. Following the interviews, we organized a closing ceremony in both cities for those in the community as an expression of gratitude for everyone involved in the study, as well to honour those who have died in the community and those who have been impacted by the losses. We hoped this ceremony would provide an opportunity to feel seen and supported.
Findings: The qualitative data provides deeper insights into the experiences of being bereaved while experiencing homelessness, as well as exposed narratives of broadly unmet needs. There were many suggestions for bereavement support (e.g., increased group and peer support, increased staff/volunteer grief & bereavement training, culturally specific supports, animal therapy). This information should aid organizations in their response to providing innovative bereavement care moving forward.
Funding: Health Canada, Health Care Policy and Strategies Program through the Pan-Canadian Palliative Care Research Collaborative Seed Grants program, the University of British Columbia Okanagan Eminence program, and the BC Centre for Palliative Care.

Do patients who die of opioid toxicity receive palliative care? A descriptive cohort study

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Background: Opioid toxicity deaths increased in Canada by over 200% from 2019 to 2021, and the majority occurred among people aged 20 to 59 years old. Given that opioid toxicity deaths are usually sudden, palliative care is typically not considered for this population.

Objectives: Our objective was to determine the proportion of opioid toxicity decedents who received palliative care and identify how they differed from those who did not receive palliative care in Ontario, Canada.

Methods: We conducted a population-level descriptive study of opioid toxicity decedents between July 1, 2015 and December 31, 2022 using health administrative data. Within this cohort, we identified decedents who received palliative care within their last two years of life, and age-matched them to those who did not receive palliative care to compare their sociodemographic, clinical and end-of-life characteristics.

Results: Among 11,645 opioid toxicity decedents, 30.1% (n=3,500) received palliative care that was initiated a mean of 335.9 days (standard deviation (SD) 237.7) before death. A mean of 4.72 days (SD 11.1) of palliative care was provided in the last two years of life. Almost all palliative care was provided in acute care (96.9%). Compared to opioid toxicity decedents who did not receive palliative care, palliative care recipients were more likely to live in lower income neighborhoods and have higher morbidity. They were also more likely to die in hospital and to receive prescription opioids indicated for pain at the end of their lives.

Conclusion: Approximately one in three opioid toxicity decedents received palliative care in the last two years of life. These encounters mainly occurred in acute care and were short term. This study highlights the need for palliative care providers to have knowledge about how to identify and care for patients who are at risk of opioid toxicity. Future studies should determine the role and benefits of palliative care for opioid toxicity decedents.

Advancing equity in pediatric palliative care: Laying the foundation for inclusive practices

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Pediatric palliative care (PPC) in Canada serves a specialized and vulnerable population - children living with serious illness and their families, representing less than 1% of those needing access to palliative care nationwide. Despite the critical nature of this care, systemic inequities in PPC remain largely unexplored. Equity-deserving communities within this underserved group face additional barriers related to geography, cultural inclusion, language, socioeconomic status, and other identity-based factors. These inequities highlight the urgent need for an intentional focus on culturally safer, inclusive, and equitable care practices tailored to the unique needs of children and their families.

Canada's Pediatric Palliative Care Alliance is a collaborative network of healthcare practitioners, researchers, families with lived experience, and advocates who envision a future where every child and their family in Canada has access to compassionate, equitable palliative care. The Sunflower - Palliative Care Podcasts are a project of the Two Worlds Cancer Collaboration, exploring all aspects of children's palliative care by providing curiosity, humor, and reflection to the world of PPC. In collaboration, these two initiatives have launched a 5-part mini-series on *Equity in Children's Palliative Care* to host conversations on these complex challenges in PPC.

Podcast episodes have brought together healthcare practitioners, individuals with lived experience and folks with significant experience serving equity-deserving communities in either pediatrics, adult palliative care or PPC settings. The dialogues aim to uncover the systemic, organizational, and individual barriers that prevent equitable access to care. The qualitative themes emerging from these discussions will provide a foundation for identifying opportunities to better address the needs of these communities in PPC.

While PPC inherently incorporates elements of cultural humility and family-centered care, these alone are insufficient to meet the diverse and intersecting needs of equity-deserving communities. Recognizing this, the podcast will emphasize the importance of collaboration, partnership, and engagement with communities and individuals with lived experience. This approach aligns with the Alliance's commitment to fostering co-designed solutions and policies that reflect the voices of those affected by systemic inequities.

Additionally, this series seeks to connect its findings to the Alliance's broader efforts, including the development of an online Resource Hub designed to provide accessible tools, training, and information for both healthcare practitioners and those with lived experience in PPC. By linking knowledge gained from this initiative with ongoing national efforts, this work will contribute to a cohesive strategy for reducing disparities in PPC.

This podcast series and the conversations sparked are the beginning of a longer journey towards advancing equity in PPC. These insights will inform future work essential to ensuring all children and their families — regardless of background or circumstance — can access the care and supports they need while navigating the difficult journey of serious illness.

Co-creating change: A public campaign strategy to overcome misconceptions and stigma in palliative care

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Background: Limited public knowledge, misconceptions, and stigma impede timely access to palliative care. Addressing this gap requires a shift from fragmented to integrated public awareness efforts.

Objectives: This study aimed to design a comprehensive public campaign strategy to address unknown, misunderstood, and stigmatized aspects of palliative care in Flanders.

Research approach: We employed an integrated approach of co-creation and Intervention Mapping, involving twenty-two citizen stakeholders, eight professionals, two communication experts, and four researchers. Following a needs assessment, we formulated change objectives and developed a logic model of change. Theory- and evidence-based change methods then guided the campaign design.

Results: The resulting strategy includes six communication principles—such as portraying people with serious illness in active positions (in control, fulfilling social roles)—and six components: (1) a dedicated network to raise societal awareness; (2) a structurally embedded, interactive website with informational, supportive, and connecting functions; (3) initiatives encouraging professional caregivers to provide timely, accurate information; (4) a multimedia campaign; (5) a palliative care ambassadors program for community outreach; and (6) low-threshold community discussions on key themes across diverse sociocultural settings.

Relevance and originality: Complex problems require comprehensive, multilayered, contextualized solutions. This co-created strategy provides general direction as well as concrete tools to enhance public understanding and engagement with palliative care, while fully acknowledging societal diversity and offering relevance beyond the Flemish context.

Equitable approaches to palliative pain management in a structural vulnerability context: A secondary analysis of community based participatory action studies

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Background: Pain management is a fundamental human right and a core element of palliative care. However, disparities in pain management outcomes exist for populations facing intersecting inequities, such as housing insecurity and poverty, which are rooted in colonialism, racism, and stigma. This study explores palliative pain management in the context of structural vulnerability, focusing on individuals who use substances, experience housing insecurity, or live in poverty.

Methods: This secondary analysis uses data from two participatory action studies that aimed to integrate equitable palliative care in community settings. Participants (n=149) included inner-city community workers (housing staff, outreach support, peer workers), a mobile clinical palliative outreach team (nurses, physicians, social workers), caregivers, patients, and decision-makers (policy makers, managers). Data sources included field notes, interviews, focus groups, and meeting notes. A reflexive thematic analysis guided by a structural vulnerability lens was applied.

Results: Findings highlight how palliative care providers worked with patients who often had unmet chronic pain needs and had developed their own strategies to manage their pain, including illicit drug use. By centering therapeutic relationship building providers worked to build trust with patients, address social determinants through care coordination and develop tailored and trauma-informed approaches to pharmacological pain management accounting for past negative healthcare experiences and responsive to social disparities. Broader social factors—such as housing insecurity, and home care, opioid prescribing and hospital policies—complicated the delivery of palliative pain management.

Conclusion: This study points to how palliative approaches to care can help legitimize pain among populations with a significant history of unmanaged and unaddressed pain. The findings emphasize the importance a relational approach to pain management, identifies how policies can perpetuate inequities, and calls for expanded support of equity-informed and community-based palliative care.

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COVID-19 public health restrictions and the provision of culturally sensitive palliative care: The experiences of the Interprofessional Health Care Team

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Background: COVID-19 public health restrictions presented a particular challenge to inpatient palliative care teams. Their focus on quality of life for dying patients and support to loved ones made these teams uniquely vulnerable to the impacts of pandemic-related rules which deeply compromised their ability to deliver culturally sensitive care. The experiences of this specialized group of front-line clinicians expose institutional barriers to the provision of person-centred end of life care and offer insight into the consequences for individuals, teams, and institutions.

Objectives: This study explored the experiences of the multidisciplinary health care team working on an inpatient palliative care unit during the COVID-19 pandemic.

Methods: A qualitative approach was used, consisting of semi-structured interviews with health care team members who volunteered in response to facility-wide recruitment signage and emails. Audio recordings were subsequently transcribed, anonymized, and analyzed using qualitative thematic content analysis and open coding.

Results: 25 individuals representing ten different health care roles participated in the study. They described a central theme of conflict between their professional duty to uphold pandemic visitor restrictions and the provision of culturally sensitive palliative care. This was underpinned by three distinct but interconnected sub-themes: (1) alterations in care, (2) challenges inherent in the development and enforcement of “rules” limiting the presence of and interactions with loved ones, (3) ensuing high levels of intrapersonal and interpersonal conflict and distress.

Conclusions: Public health restrictions have a powerful impact on institutional practices that significantly compromise the abilities of inpatient palliative care teams to provide the culturally sensitive care they aspire to. In this study, participants described lasting negative impacts for themselves, their team, and for the patients they served during the three-year period that they were required to enforce increasingly contentious public health restrictions.

Relevance: This study adds to others done during the COVID-19 pandemic that explore the experiences of front-line health care providers but is unique in its specific focus on the interprofessional team serving an inpatient palliative care unit situated within a larger health care facility. The study highlights the challenges of implementing public health mandates within health care facilities, and institutional barriers to prioritizing the needs of dying patients, their loved ones, and the teams caring for them. Arising from this are challenging questions regarding institutional values and to what degree health care facilities are prepared to adapt to better serve these important populations.

Funding: This study was funded by a research grant from the foundation of the institution where the study was conducted. In-kind support was provided by the institution and affiliated clinical programs.

Advancing the Care Experience for patients receiving Palliative care as they Transition from hospital to Home (ACEPATH): Using an innovative co-design approach to create an intervention to improve patient and family caregiver experiences

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Background: Transitions from hospital to home can be emotionally distressing and logistically challenging. Previous hospital-to-home interventions have not been developed in partnership with patients receiving a palliative approach to care or their family caregivers, or been tested in Canadian acute or subacute care settings.

Objectives: To co-design an intervention (Advancing the Care Experience for patients receiving Palliative care as they Transition from hospital to Home [ACEPATH]) to improve the experience of hospital-to-home transitions for patients receiving a palliative approach to care and their family caregivers across acute and subacute care settings in Ontario.

Research approach

1. Development of materials for co-design workshops (CDW) to communicate findings from prior research.
2. Engagement through CDWs with patients and family caregivers to understand challenges, identify metrics, and actions that would improve the transition experience.
3. Healthcare providers (HCPs) provided feedback on how low-fidelity prototypes might fit into their workflow.
4. Testing of a high-fidelity prototype in a mock discharge scenario with patient, family caregiver, and HCP participants.

Relevance: This work utilized a unique approach to develop a co-designed intervention to enhance quality of care and patient/caregiver satisfaction with hospital-to-home transitions for those receiving a palliative approach to care. The intervention engages hospital and community-based HCPs to ensure comprehensive care delivery across care settings.

Originality: To our knowledge, this is the first hospital-to-home intervention in Canadian acute or subacute care settings to be co-designed by patients and caregivers and deemed feasible by HCPs.

Relevance to conference theme: Patients and caregivers were centered in the co-design process to ensure they felt prepared and supported throughout their transition from hospital to home. HCPs were involved to ensure the intervention's fit within their current workflow.

Funding: This work was funded by the Canadian Institutes of Health Research.

Building system capacity for home visits for patients near end of life: A mixed methods study

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Background/context of the study: Despite known benefits, many Canadians do not receive adequate physician and nurse practitioner (NP) home visits in their last year of life. Socioeconomic, geographic, racial, and other disparities further perpetuate inequities in the receipt of home visits. We need to better understand the factors that prevent/facilitate physicians' and NPs' willingness to provide home visits to ensure equitable access.

Objective: To understand physician and NP perceptions of factors that influence the provision of home visits at the end of life.

Research approach: Our sequential explanatory mixed methods study included a pan-Canadian survey followed by interviews designed to provide insights into the survey findings. Physicians and NPs from across Canada who do and do not provide home visits to adult patients in their last year of life completed an online survey (April-November 2024). Survey respondents could choose to participate in an optional, virtual interview. Semi-structured interviews investigated deeper meanings of survey findings and were analyzed using thematic analysis.

Relevance: While unsatisfactory remuneration is commonly cited as a major barrier to providing home visits, survey participants did not highlight financial incentives as a barrier or facilitator. To scale up home visits, interview participants suggested provincial/territorial and federal governments should address workforce shortages, prioritize education/training, and promote interprofessional teams.

Originality: This is the first pan-Canadian study exploring facilitators and barriers to the provision of home visits at the end of life by both physicians and NPs.

Relevance to conference theme: By considering factors that prevent/facilitate willingness to provide home visits, our study seeks to explore equitable access to home visits, regardless of socioeconomic status, geographic, racial, and other factors. Resulting policy actions could improve access to home visits across various jurisdictions and for those from equity-deserving groups.

Funding: This study is funded by a CIHR Project Grant (Fall 2022).

"I wish I knew": Assessing older adults' perceived and actual knowledge of their partners' end-of-life preferences

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Objectives: Despite the importance of surrogate decision-making by partners at the end of life, there is only limited research on older adults' knowledge of their partners' end-of-life preferences. Hence, this study investigates older adults' perceived and actual knowledge of their partners' preferences for end-of-life care and medical treatments.
Methods: We analyzed data from 667 respondents aged 50+ from Wave 8 (2019/2020) of the Survey on Health, Ageing, and Retirement in Europe in Switzerland. We assessed respondents' actual knowledge by comparing their perceptions of their partners' preferences for end-of-life care and medical treatments with the partners' self-reported preferences. Additionally, respondents were asked to rate their perceived knowledge of their partners' wishes. Associations were assessed using multivariable regression models, adjusting for social, health, and regional characteristics.
Results: Respondents' actual knowledge of their partners' preferences varied, with the share of correct answers ranging from 35% to 81% depending on the preferences. More than 80% of respondents felt that they knew their partners' end-of-life and medical treatment preferences "rather" or "very" well, and those respondents were more likely to identify their partners' preferences accurately.
Discussion: Improved communication between partners regarding their end-of-life preferences could significantly enhance surrogate end-of-life decision-making. However, since older adults' perceived knowledge of their partners' preferences seems overly optimistic, they may see little need to initiate such conversations by themselves, emphasizing the need for external educational interventions such as role-plays or case study discussions through, say, the community, or healthcare system to encourage such conversations.
This study has since been published in full in Innovation in Aging (2025), DOI: 10.1093/geroni/igaf038.

Recognizing and valuing caregivers to improve life and death experiences of underserved and excluded communities

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Background: Public Health Palliative Care values the essential roles of friends, family, and community in care, dying, death and grief. While informal or 'family' caregiving has been widely studied, less is known about caregiving in contexts of inequity such as homelessness and unstable housing.
Objectives/purpose: This ethnographic study informed by critical perspectives and integrating social justice and health equity approaches sought to learn about caregiving in contexts of inequity.
Research approach: Over a period of 27 months, we conducted 300 hours of participant observation and 44 interviews with people living with life-limiting conditions, their caregivers, and service providers. A thematic analysis illustrated three main aspects: (1) relationships and roles in informal caregiving; (2) identifying and perceiving caregivers; and (3) bio-legal privileging and exclusion of caregivers.
Relevance: Caregiving in this study challenged assumptions embedded in health and social policies, and palliative care practice, that people with life-limiting conditions are accessing care from those they are biologically or legally related to. Instead, people accessed care from a constellation of formal (e.g., case managers, housing workers) and informal (e.g., neighbors, friends, partners/spouses, bio-legal family) caregivers.
Originality: This original study contributes to a relatively new area of research on informal caregiving in contexts of inequity and highlights the need to better recognize, engage, and support all those participating in caregiving.
Relevance to the conference theme: This study illustrates research approaches that can uncover invisible care work. It offers a critical interrogation of the landscape of palliative care, while offering ways forward that incorporate equity-oriented health care, social justice, community engagement, and citizen involvement to improve the lives and deaths of people within underserved and excluded communities.
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Compassionate, Dementia Inclusive Communities: Innovations in volunteer navigation

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Background: This project addresses an urgent need for practical solutions to assist persons living with dementia and their care partners in meeting their social determinants of health. To achieve this, we are using a volunteer navigation program called Nav-CARE alongside an inter-organizational compassionate dementia-inclusive community approach to enhance supports for persons living with dementia and their care partners.
Purpose: The purpose of this project is to combine, implement, and evaluate three evidence-based strategies of community volunteerism – volunteer navigation, compassionate communities, and dementia inclusive communities – to

improve the care of persons living with dementia, including care partners. In this presentation we will present the theoretical grounding of the project including a Compassionate Dementia Inclusive Communities (CDIC) Toolkit and specialized volunteer training.

Research approach: The principles of community-based research inform this project. Organizational leads from within six diverse Canadian communities will build coalitions among key community-based organizations that serve persons living with dementia. Together these organizations will educate their volunteers using common navigation training developed to meet the needs of this population. Communities will then implement and evaluate two interventions designed to build community capacity for dementia care.

Relevance: Innovations such as volunteer navigation, compassionate communities, and dementia-inclusive communities have great potential to improve a public health approach to palliative care. In this project we are combining all three approaches in a single project to determine the effect on community capacity. A CDIC Toolkit has been created, which will be revised based upon the findings of the project, and made available to other communities seeking to apply a similar approach.

Trialling end of life doulas as part of the UK National Health Service: What worked. . .and what didn't!

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Historically, end of life doulas have always been part of the community. With the introduction of the UK National Health Service, death moved behind closed medical doors, eroding death literacy amongst the community. Incorporating end of life doulas as part of the NHS is somewhat contentious. This innovative project sought to explore what this might look like in practice and whether the potential benefits might outweigh the costs, and more importantly reveal some lessons moving forward.

Between December 2023 and August 2024, 12 doulas provided support to 25 people at the end of life, and their families, living in two London boroughs. A contribution analysis approach was used to explore whether and how doulas made a difference to people, and their families, at the end of life. Individual interviews with people involved in the project, group discussions with doulas, testimonials from family and service providers, and quantitative data were all used to build a picture of the complex contribution made by doulas in this setting.

Doulas provided a range of support including visits, respite for family and carers, emotional and practical support, conversations about advance planning and advocacy. Those at the end of life, as well as their families, felt deeply appreciative and grateful for the support of doulas, with many families expressing that they felt more at peace, and less fearful and stressed in the face of a difficult, emotional process.

Early data suggests that having doula support potentially reduces hospital admissions and increases likelihood that people will die in their preferred place of death. However, setting up the project was time-consuming, both in relation to its promotion but also the need for procedures and processes to meet regulatory requirements.

Dying well in the UK is often reserved for only those who can afford it. Having doulas as part of the health system could increase the likelihood for more people at the end of life to have access to life enhancing non-medical practical, emotional and spiritual support.

This project offered exciting insights into the value and viability of integrating doulas as part of palliative care. Trialling such initiatives is vital at a time when the NHS is stretched to capacity and looking for cost-effective solutions, particularly those that might empower the community to support itself. However, delivering doula support as part of an established health system without threatening the integrity and person-centred ethos of doula care remains a challenge.

Funding: This project was funded via an NHS innovation grant in London, UK.

Black and white older adults' end-of-life experiences: Does hospice use mitigate racial disparities?

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Background/context: Black Americans have long faced structural barriers in accessing high-quality hospice care, often resulting in poorer death quality compared to their White counterparts. While previous research has established the presence of racial inequalities in healthcare access, limited studies have explored how these disparities manifest in death quality and how these death experiences relate to assessments of death quality.

Objectives/purpose: This study investigates how the COVID-19 pandemic affected death quality and whether these impacts differed for White and Black decedents. We also evaluate the extent to which hospice and palliative care moderated these associations. Specifically, we hypothesized that pandemic-related disruptions in care led to poorer death quality, with more pronounced effects for Black decedents, and that the presence of hospice or palliative care would moderate these negative outcomes.

Research approach: Data are from the Health and Retirement Study (HRS) Core and Exit Interviews conducted between January 2018 and September 2023. Our analytic sample included 2,498 decedents (450 Black, 2,048 White). Multivariable OLS and logistic regression models were used to estimate the associations between race, hospice use, and our two EOL experience outcomes.
Relevance: Proxies for Black decedents reported higher perceived death quality than those for White decedents, despite evidence of greater structural disadvantage. However, perceived care concordance was significantly lower among Black decedents. Hospice care was associated with improved perceived death quality for Black decedents but not for Whites. When accounting for socioeconomic and death experience controls, hospice care did not moderate perceived care concordance. Our findings highlight the importance of considering expectations, context, and reference group comparisons when interpreting subjective EOL measures. Expanding equitable access to high-quality hospice care may help reduce persistent racial disparities, but interventions must also address how care is experienced, evaluated, and aligned with individual preferences.
Originality: This study is among the first to use HRS data to assess subjective death quality through proxy-reported evaluations and investigate differences in death quality based on race. It provides novel insights into the relationship between race, healthcare utilization, and subjective death quality experiences.
Relevance to conference theme: By investigating the impact of hospice care on death quality this study aligns with the conference theme. Our findings demonstrate the necessity of targeted interventions to reduce health disparities and ensure high-quality, patient-centered care for all populations.
Funding: The Robert Wood Johnson Foundation Evidence for Action Grant.

Ethical challenges in accessing support resources in perinatal palliative care: A normative analysis through the lens of relational ethics

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Context: Parents continuing a pregnancy following a life-limiting fetal diagnosis face significant ethical and practical challenges regarding access to and adequacy of perinatal palliative care (PPC) support resources. in accessing and obtaining adequate perinatal palliative care (PPC). These arise throughout the parental journey - from diagnosis and decision-making to birth and bereavement - and involve the availability, quality, and coordination of medical, social, and community-based support. Despite increasing recognition of the role PPC can play, significant disparities in access and a lack of tailored, holistic support persist. This situation highlights the urgent need for an ethical lens to understand and address systemic inequities in PPC service delivery.
Purpose: This study examines the ethical dimensions of accessing PPC support resources through a normative analysis grounded in relational ethics. Its goal is to shed light on the structural and organizational barriers that undermine equitable, personalized care for families navigating PPC services.
Research approach: A normative analysis was conducted based on a literature review, guided by Rollo's (2022) *A Relational Ethics of Pregnancy* and Baylis et al.'s (2008) *A Relational Account of Public Health Ethics*. Together, these frameworks emphasize the relational nature of care and justice, making them well suited for analyzing access to PPC services. The analysis identified three major ethical tensions: (1) Disparities in access, where regional and socioeconomic differences limit families' ability to obtain necessary support; (2) Standardization versus individualization, highlighting tensions between uniform service provision and families' unique values, beliefs, and emotional needs; and (3) Fragmentation of support networks, referring to a lack of seamless collaboration across medical, social, and community services, leading to disrupted care pathways and heightened isolation.
Relevance and originality: By applying a relational ethics lens, this study advances understanding of systemic inequities in PPC, with direct implications for clinical practice, policy design, and future research. Its relational focus exposes hidden ethical blind spots within existing PPC structures, providing actionable insights for aligning services more closely with the lived realities of families.
This approach is highly relevant to the conference theme of *Innovative Approaches to Equity in Palliative Care,* as well as discussions about *Community Participation in Palliative Care,* by underscoring the role of social and community-based support in fostering equitable, accessible care.
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Diverging perspectives: How informal caregivers and physicians understand barriers to end-of-life care

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Background/context: Despite the expansion of end-of-life services in the United States, there remains an unmet need among older adults for advance care planning (ACP) and hospice. Prior literature has identified inadequate end-of-life counseling and limited ACP education as barriers to end-of-life planning and decision-making. This work has failed to investigate how physicians' and caregivers' perceptions of care barriers translate to unmet needs for ACP and end-of-life services. Moreover, patient-physician communication may be complicated by the emotional toll of care at the end of life, which may exacerbate discrepancies in perspectives.
Objectives/purpose: To assess the perceptions of barriers to end-of-life care by physicians and informal caregivers of recent decedents and examine the implications of the potential differences in these perspectives on care delivery.
Research approach: We conducted three focus groups with physicians who routinely provide care at the end of life and two focus groups with former informal caregivers of recent decedents. We recruited participants through in-person flyers, social media advertisement, and partnerships with local social service organizations. Physician focus groups were conducted over Zoom, while caregiver focus groups were conducted in-person. All groups were led by a trained focus group leader, audio-recorded, and professionally transcribed. Data was analyzed using NVivo with a constructivist grounded theory approach.
Results: Physicians and caregivers held differing perspectives on the barriers to end-of-life care, with physicians emphasizing cost as a significant barrier for patients, overlooking the interpersonal and informational barriers most commonly reported by caregivers. Physicians did not evaluate similarly the quality of interactions about end-of-life care, with caregivers reporting dissatisfying experiences and a lack of attention to the emotional toll they experienced. These misaligned perspectives regarding the quality of end-of-life care interactions prevented patients and caregivers from pursuing or enacting ACP, and sometimes led to the provision of care that caregivers believed was not concordant with their loved ones' wishes.
Relevance: Insights from this study will guide future policy recommendations to reduce barriers to end-of-life care that may be driving unmet needs in advance care planning and hospice use.
Originality: This study is among the first to directly contrast physician and caregiver perspectives on barriers to end-of-life care and reveals how misalignment in perceived obstacles can disrupt care planning and delivery. Our study directly compares the perspectives of healthcare providers and caregivers, identifies points of divergence in their perceptions, and assesses the implications of this misalignment on ACP and end-of-life care.
Culturally sensitive palliative practices: Culturally sensitive palliative care must consider experiences of healthcare marginalization and barriers to care to ensure that all patients receive compassionate, goal-concordant care at the end of life.
Funding: The Robert Wood Johnson Foundation Evidence for Action Grant.

Patient and caregiver-reported acceptability of an "automatic" supportive and palliative care referral for advanced lung cancer patients with translation into clinical practice

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Background: Timely palliative care interventions can alleviate distress people and families experience after a diagnosis of an incurable cancer. Some patients access resources in a timely manner, whereas others struggle to find and navigate the care and resources they need. This study, co-designed with patients and providers, evaluated the acceptability of a phone call offering an early palliative care consultation for all patients newly diagnosed with stage IV Non-Small Cell Lung Cancer.
Objectives: The objective of the research study was to determine acceptability of a phone call from a supportive and palliative care (SPC) nurse offering consultation automatically after first oncologist appointment. A secondary gain was for patients to have the opportunity to sit down in their own homes with a SPC nurse to discuss community resources and support.
Research approach: SPC nurses screened clinic lists at a tertiary cancer center and called all eligible patients to offer a consultation. Eligibility: >18 years, newly diagnosed/suspected Stage IV NSCLC and had first oncologist visit. Patients could have a cancer therapy plan pending, confirmed, or have no further care at the cancer centre. Patients/caregivers were surveyed about the acceptability

(5-point Likert scale) of the phone call, using Sekhon's Framework of Acceptability domains.

Relevance: This study revealed nearly all patients/caregivers found the call offering a SPC consultation to be acceptable and majority accepted the consultation. Further qualitative study looking at patients' views of the consult was also overwhelmingly positive. We attempted to avoid inequities by automatic referral, however it was found that patients who decline the consultation are more likely to be living with factors associated with deprivation (older age, male sex, and socioeconomically deprived). We have now transitioned these automatic calls to become part of our normal practice. By first identifying and understanding inequities that exist within our healthcare system, we may then embark on solutions

Originality: To our knowledge, this was the first study that looked at automatically calling patients to offer PC, without waiting for referral. The systematic nature of the intervention may reduce any bias in which patients are referred for an early palliative consult.

Engaging young adults in conversations about death and dying through arts-based approaches

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Background: Denial and cultural silence around dying and death are significant social issues of our time, and the impact on young adults has been greater than for other groups. 'Death literacy' has emerged as a field within a larger education movement to support individuals, health and social professionals and the public more broadly through awareness, understanding and dialogue. Death literacy encompasses cultivating the knowledge and skills to access, understand, and act upon end-of-life and death care options. Creative strategies, such as arts-based approaches, may be particularly relevant to the needs of young adults, yet research has been limited to date.

Objectives: The aim of this knowledge translation project was to translate existing palliative care narrative data using arts-based approaches into animation and other arts forms as a way to emotionally engage with young adults on this topic and consider creative products within future educational initiatives.

Research approach: We co-designed a pilot course for undergraduate art and design students, involving researchers, students and faculty, to explore arts-based approaches to understanding narrative, palliative care qualitative data. The data came from a PhD dissertation exploring social (family, healthcare provider) experiences of waiting with children in palliative care. Selected, anonymized text (focused on empathy, waiting, grief, illness, suffering, and death-related themes) from 145 journal entries of 18 healthcare providers was used in the pilot course. Four students enrolled and worked with this material to create different arts-based forms (e.g., collages/moodboards, sketches, digital drawings, sequential narratives/storyboards, journey mapping). Students were guided to select moments, emotions, and feeling states to reflect in their artwork.

Relevance: Young adult students were open to talking about concepts of dying and death and wanted to engage further in this type of knowledge creation around sensitive health topics. This work advances knowledge on how to engage with young adults about death and dying using art-based approaches, and how art-based approaches can communicate to broad audiences about death and dying within clinical care and beyond.

Originality: We contribute creative ways of compassionately and emotionally engaging young adults to support communication about dying and death and other sensitive health topics.

Starting a Compassionate Community: Exploration of stakeholder experiences mobilizing neighbourhood assets

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Background: Asset-Based Community Development (ABCD) builds on the existing resources and social capital within communities. In the context of Compassionate Communities, ABCD can be used to enable individuals, associations, and institutions to incorporate topics of serious illness, caregiving, death, and loss into their current programs in a way that is meaningful for them. Additionally, it can help them enhancing their already existing capacity to provide care and support for people faced with such challenges. However, there is a lack of knowledge about which specific assets are useful to start and develop a compassionate community and what challenges local stakeholders and neighborhood residents encounter in using and mobilizing these assets.

Aims: Identify neighborhood assets that contribute to the development of Compassionate Communities in two Flemish municipalities in Belgium (Herzele and Sint-Kruis) and explore challenges that local stakeholders and neighborhood residents encounter in using and mobilizing these assets.

Methods: Qualitative study with 6 focus groups (n=33), 28 individual interviews and stakeholder meeting observations (Sint Kruis: n= 67, Herzele: n=23). Participants included neighborhood residents, and local stakeholders including neighborhood police, local merchants and neighborhood committee coordinators. Data was analyzed using thematic analysis.

Results: Identified assets for developing compassionate communities can be divided into 4 subcategories, namely (1) physical, (2) social, (3) service, and (4) financial. Physical assets included green spaces, open areas and accessible buildings in the neighborhood. Social assets involved community connections, peer relationships, level of social support of community members, and participation in neighborhood activities. Service assets included presence of local organizations, neighborhood services, and collaborations with other neighborhood committees. Financial assets referred to available grants (e.g., neighborhood cheques) and the existence of a financial reserve of the neighborhood committee. Qualitative data suggested that these assets can contribute to neighborhood cohesion around serious illness, death, and loss, and provide a foundation for creating a compassionate community. Challenges of stakeholders that influenced the utilization and mobilization of these neighborhood assets included time constraints of stakeholders, lack of vision, premature action, centralized decision-making and lack co-creation.

Conclusion: The study underscores the importance of physical, social, service, and financial assets in starting and developing a compassionate community, while also recognizing challenges in effective asset utilization and mobilization. Addressing challenges such as time constraints, lack of vision, and centralized decision-making can enhance the community's ability to leverage these assets for sustained impact. Additionally, the findings of this study offer valuable insights for guiding future asset mapping exercises in different contexts.

Community-based palliative care approach: A potential solution to address gaps in support for patients and families seeking Medical Assistance in Dying

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Background: Following the introduction of Bill C-7 in 2021, Medical Assistance in Dying (MAiD) processes in Canada are categorized into two tracks with distinct safeguards. Track-1 applies to eligible individuals whose natural death is reasonably foreseeable, while Track-2 applies to those whose death is not foreseeable. Although some Track-1 MAiD patients and most Track-2 patients have a prognosis exceeding one year, the decision to proceed with MAiD and set a date can signify the commencement of their end-of-life phase. Seamless access to MAiD and palliative care can significantly enhance the end-of-life experiences of these patients. However, patients whose death is not imminent or those from equity-deserving groups may not qualify for or have access to palliative care. Island Health has some of the highest MAiD provision rates in British Columbia. The MAiD team collaborates well with palliative services to support patients at Island Health, making it an important setting to examine the challenges and opportunities that come with legislative expansions. This study **aims** to: (1) explore the perspectives and experiences of healthcare providers, patients, families, and community support representatives with MAiD, and (2) identify gaps in resources and support for patients, family members and healthcare providers with Track-2 MAiD at Island Health.

Methods: Ethics approval was obtained for two separate studies. The first was a survey-based study, collecting data from 55 patients and families and 72 healthcare providers. The second study used convening and collaborating approaches, gathering data (minutes, flipchart entries, and participant feedback) from two discussion sessions with 41 participants, including patient partners, healthcare providers, and community representatives. A concurrent parallel design was used for analysis, applying a descriptive approach, with findings reported using generative codes.

The **findings** highlight significant gaps in support and care for MAiD patients and families. The key findings are organized into the five main themes: 1) the spread of misinformation and mistrust, 2) barriers to access and involvement, 3) concerns regarding the impact of Track-2 MAiD on equity-deserving groups, 4) inadequate support for patients requesting Track-2 MAiD, and 5) challenges experienced by healthcare providers.

Implications: The findings have informed systems-level changes within Island Health's MAiD program. Further research aunnd initiatives are essential to improving the support and end-of-life experiences of patients seeking MAiD and their families. Specifically, there is a need to better understand and address the holistic needs of patients facing health inequities and their families, by providing a comprehensive continuum of care that integrates palliative approaches and fosters community engagement.

We received funding from Michael Smith Health Research BC, the Canadian Association of MAiD Assessors and Providers, and Vancouver Island University to support this work.

Building a causal model for the relationship between Death Literacy, its theorized determinants, mediating factors, and outcomes: A qualitative mixed-methods study

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Background: Death Literacy is proposed to be a resource for individuals and communities, providing them more control over their own end-of-life care and that of those close to them. Its society-wide development has been recommended, for instance, by the Lancet Commission on the Value of Death. However, due to its novel nature, the concept needs further scientific underpinning. There is a lack of knowledge about (1) what factors influence Death Literacy and (2) what outcomes are associated and causally connected to it.

Objectives/purpose: This study aims to develop an evidence-informed conceptual model of the causal relationships between Death Literacy, its theorized determinants, mediating factors, and outcomes.

Research approach: We conducted a qualitative mixed methods study, combining an evidence synthesis of a scoping literature review with a series of expert panels. The scoping review was executed following Arksey and O'Malley's framework and the PRISMA-Scr guidelines. 5 databases (PubMed, Embase, Web of Science, Scopus, and PsycInfo) were searched for articles investigating or discussing causal relationships in which critical literacy, applied to end-of-life outcomes or experiences, serves as a component of the causal path. Our search resulted in 10054 articles (5409 after duplicate removal). Included articles are analyzed for relevant variables, divided into categories (exposure, outcome, mediator, or modifier).

Additionally, we conducted expert panels with international academics (n=10) and local experts by experience (n=10). Inductive, reflexive thematic analysis is used to identify additional determinants, mediators, or outcomes.

Based on this input, we build a causal model using the Evidence Synthesis for the Construction of Directed Acyclic Graphs (ESC-DAGs) methodology. Variables identified in the scoping review and expert panels will be used to draw an integrated DAG/causal model. In a next stage, this model will be operationalized and tested quantitatively.

Relevance: Our work results in an integrated causal model about Death Literacy. As such, it provides 1) a conceptual and analytical tool for future research on Death Literacy and 2) an evidence base for programs and interventions aiming to leverage Death Literacy in society. Given the high expectations for Death Literacy and the strong calls to develop it, this understanding is highly needed.

Originality: This is the first review of Death Literacy and the first study to build a causal model illustrating how this concept operates and affects end-of-life care and support outcomes.

Relevance to conference theme: Death Literacy fosters a community's capacity to respond to the challenges of serious illness, dying and grief, making its members better equipped to provide care for one another. Insight in how it is developed is crucial for interventions and research promoting community-based end-of-life care.

Exploring the experiences of healthcare professionals caring for the dying in intensive care: A phenomenological approach

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Background: Care of the dying in intensive care is complex and emotionally intense. Professionals face challenges in providing optimal end-of-life care and report a lack of institutional and educational support. Caring for the dying is a social concern requiring understanding relational alongside scientific aspects to better support intensive care professionals in end-of-life situations.

Purpose: To explore experiences of healthcare professionals caring for the dying in intensive care.

Research approach: A two-phased study following heuristic inquiry and hermeneutic phenomenology was conducted in three intensive care units in community, tertiary and general Canadian hospitals. Phase one involved immersion into the lived experience by attending eight shifts in intensive care and conducting two semi-structured interviews with purposely sampled intensive care professionals. Phase two, nine semi-structured interviews with purposively sampled intensive care professionals. Analysis fused understanding of lived experiences from both phases drawing on Moustakas's framework for heuristic inquiry and an inductive analytical hermeneutic phenomenological model.

Relevance: Intensive care professionals are changed by feeling embodied emotions when caring for the dying. Their emotional responses, including sorrow and wonder, deepen an understanding of the relational needs of the dying and the value of engaging in meaningful interactions at end-of-life. Meaningful interactions are experienced in moments that seamlessly integrate into their demanding roles. Leaning into and learning from this meaningful work is profound and builds the sustenance needed for intensive care professionals to continue to intentionally care well for themselves and others.
Originality: Developing experiential knowledge about caring for the dying in intensive care clarifies how to navigate relational aspects of care within a fast paced scientifically driven environment. Practical guidelines rooted in the inherent connections between individuals are essential for meaningful support for everyone facing the challenges of being with death.
Relevance to the conference theme: The intensive care environment, designed to support life, faces the profound challenge of offering the same dedication to supporting death when it becomes inevitable. Recognizing the relational aspects of caring for the dying as embodied social practices, rooted in practical, person centered and compassionate caring approaches is essential to creating meaningful outcomes at end-of-life.

Using co-creation to adapt a practice support tool to be more culturally sensitive

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The Serious Illness Conversation Guide (SICG^{TM}) is an evidence-informed practice tool used in Canada and internationally to discuss goals, wishes, and fears with people facing life-limiting illness. It has been tested and adapted with people of European and African American descent, and with the Indigenous peoples of New Zealand. However, it had not been tested with Indigenous people living in British Columbia.

To adapt the SICG to be more culturally safe with diverse populations, two provincial organizations collaborated to:

1. Co-design an adapted SICG with Indigenous People and healthcare providers (HCPs) working with Indigenous communities.
2. Test the adapted guide (SICG-r) with people of culturally diverse backgrounds.

Data was collected from HCPs through surveys and focus groups. Nurses working in Indigenous communities invited the project team to join Elders' gatherings as guests, where we hired caterers from their communities to provide a meal. Through hearing their stories, we sought to understand how this type of conversation had impacted the Elders in the past, how they would perceive the questions, and the importance of context. We used a co-design, iterative methodology to make and test revisions.

The SICG-r was further tested using the same methodology with non-Indigenous people of European, Chinese, and South Asian descent.

To our knowledge, this relationship-based, co-design methodology had not been used with Indigenous people in B.C. to adapt tools supporting serious illness conversations. The methodology could be used by seminar attendees to adapt other practices to be more culturally sensitive.
Results: People with lived experience and HCPs agreed the SICG could cause harm if used by a HCP with no prior relationship, context is important and family must be involved, without limits on how many or who that would include. We created a preamble for HCPs to ask the person beforehand who they would like to be present, when and where the conversation should be. We added a post-script to acknowledge that information shared belonged to the person, asking permission to share it with other HCPs and offering a copy of documentation.

The formal language in the original SICG was perceived as reinforcing power differentials, so some of the questions were modified to simpler language. For example, "What are your most important goals if your health situation worsens?" was changed to "If your health gets worse, what's important to you?" The Dignity question, "what do I need to know about you to give you the best care possible?" was added, as the Elders felt this would prompt the person to share spiritual and traditional practices.

The SICG-r was confirmed by diverse participants as a tool that could support more culturally safe, relationship-based interactions.

POSTERS

Advanced care planning in patients with cancer in palliative care: A meta-synthesis

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Background: Advanced Care Planning (ACP) is a critical process in palliative care (PC), particularly for patients with advanced cancer. While ACP has been shown to enhance patient autonomy and reduce anxiety, its implementation remains inconsistent due to emotional, social, and institutional barriers. Existing literature has predominantly explored ACP in the context of multiple chronic illnesses, with limited focus on the unique experiences of advanced cancer patients. This systematic review and meta-synthesis address this gap by examining patients' perspectives and experiences regarding ACP and advance directives within a PC setting.

Objectives: This study aims to synthesize qualitative evidence on how advanced cancer patients perceive and experience ACP.

Methods: A systematic review and meta-synthesis of qualitative studies published between 1991 and 2024 was conducted. Searches were performed in six databases: CINAHL, Cochrane, OVID, PubMed, Scopus, and ScienceDirect. Studies were assessed using the Joanna Briggs Institute Critical Appraisal Checklist, and thematic synthesis was applied to data from 20 selected studies involving 534 participants.

Results: Six major themes emerged: (1) Meaning of ACP, (2) Initiating ACP, (3) Barriers and facilitators, (4) Communication in ACP, (5) Outcomes of ACP, and (6) Needs and wishes in ACP. Findings indicate that ACP is perceived as a complex, evolving, and shared process. Emotional readiness, trust in healthcare providers, and culturally tailored communication strategies are essential facilitators. Conversely, reluctance, avoidance behaviors, and institutional limitations act as significant barriers. The study highlights the importance of integrating ACP into routine PC discussions to ensure goal-concordant care and improve patient and family preparedness for end-of-life decisions.

Relevance: This research contributes to the understanding of ACP from the perspective of advanced cancer patients, offering critical insights for healthcare providers, policymakers, and researchers. The findings emphasize the need for patient-centered ACP approaches that address emotional, psychological, and systemic barriers. Implementing structured, culturally sensitive ACP interventions can enhance patient participation and improve end-of-life care quality.

Originality: This study provides a novel synthesis of qualitative data focused exclusively on advanced cancer patients, distinguishing it from prior research that grouped ACP experiences across multiple chronic diseases. By capturing the nuanced challenges and preferences of this patient population, the findings offer valuable direction for developing more effective ACP interventions.

Relevance to conference theme: The study aligns with the conference theme by addressing a fundamental aspect of palliative care—patient autonomy and shared decision-making in ACP. It underscores the role of healthcare professionals in facilitating meaningful ACP conversations and shaping policies that enhance patient-centered end-of-life care. This work provides evidence-based recommendations for overcoming barriers and fostering ACP discussions that respect patients' values, goals, and cultural contexts.

Exploring the relationship between religious and public health communities to advance community-based palliative care

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Background: Religion and public health, when understood in their broadest sense, are systems of knowledge and practice that seek to improve the wellbeing of individuals and populations. In the context of palliative care, these systems can intersect to advance quality-of-life for those living with serious illnesses. Public health can facilitate equitable access to culturally safe care, while religion can provide meaning, purpose, strength, and supportive communities.

Purpose: This study explores the relationship between religion and public health by examining the experiences of public health practitioners in engaging with religious communities, with the aim of informing inclusive and innovative care approaches.

Research approach: A framework analysis was conducted on 15 interviews with North American public health practitioners, including palliative care physicians, from diverse religious and ethnic backgrounds.

Relevance: Palliative care physicians expressed that religion and spirituality are critical elements for their practices. For example, one participant stated: ". . . the work that we do in things like conversations or care at the end of life, people's choices, what people end up getting, is very impacted by religious norms in society..." However, when working at a broader system level, findings revealed that public health professionals often engage religious communities in instrumental ways to advance their agenda, rather than as genuine partners. For example, another participant stated: "And so it might be easy for researchers or like institution to be able to say, we're going to use the institute, the faith-based institutions as places to do good research or lots of research or to gather data or to get input." While some religious communities are compliant with such transactional interactions, many are reluctant. To advance meaningful engagement, participants share numerous strategies consistent with the principles of community-engaged research (e.g., engaging with religious communities with sincerity, humility, transparency, and valuing the knowledge these communities possess).

Originality: This study is among the first to bridge the gap between public health, religion, and palliative care, offering insights into their collaborative potential for equitable and responsive community-centered care. Notably, results suggest that effective engagement between public health and religious communities is based on foundational principles such as trust, transparency, and the need to identify shared goals. Putting these principles into practice in palliative settings may challenge current structures and financing mechanisms (e.g., building accountability towards communities rather than funders), and raises critical questions around concepts such as expertise, access to knowledge, as well as around how research problems are identified and prioritized. Incorporating religious and spiritual dimensions into public health and palliative care education could serve as a foundation to foster more inclusive practices.

Relevance to the conference theme: This study informs the conference themes of culturally sensitive practices and developing models of care that emphasize community participation.

Barriers and facilitators of social support initiatives for older 2SLGBTQIA+ people in British Columbia, Canada

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Background: Research indicates that involuntary loneliness and lack of community support is more prevalent among older people who are part of sexual and gender minority populations (2SLGBTQIA+) compared to the general population. A life course where identities were criminalized, pathologized, and often not socially accepted has been pointed out as one explanation for this disparity. Furthermore, social support initiatives targeting older adults in-general may inadvertently hinder the participation of 2SLGBTQIA+ people due to underlying heteronormative expectations.

Objectives: To investigate barriers and facilitators of social support initiatives for older 2SLGBTQIA+ people British Columbia, Canada.

Research approach: A rapid review of the research literature and seven qualitative interviews with people working in organizations with programs to address 2SLGBTQIA+ social isolation were completed.

Relevance: Preliminary findings indicate that root causes of social isolation and loneliness include: Lifetime discrimination, current experiences of rejection, social network dynamics, lack of inclusive support, and the impact of COVID-19. Our interviews focused on uncovering elements of programs successfully addressing social isolation and suggest that small scale initiatives may work as well or better than large scale programming. These findings may inform both policy and practice regarding social support for older 2SLGBTQIA+ people.

Originality: This original research addresses a knowledge gap in public health regarding the needs and contexts of older 2SLGBTQIA+ people.

Relevance to the conference theme: 2SLGBTQIA+ people are an underserved population for which community support and a safe space is crucial at the end-of-life. This research highlights ways in which social support initiatives can innovate to create safer spaces for this group.

Funding: Valerie Kuehne Undergraduate Research Award, The Jamie Cassels Undergraduate Research Award, Forte (Sweden)

Developing a community-based palliative care service to address social determinants of health and meet the needs of underserved populations

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Background: People living with serious illness alongside the life-limiting conditions of homelessness, poverty, racism, and ableism experience accelerated aging, shortened life expectancies, and poorer quality of life at the end of life. The Palliative Outreach Resource Team (PORT) is a community-based service to meet the palliative needs of underserved populations alongside their social determinants of health (SDOH) needs.

Objectives/purpose: We formed a partnership between community organizations, health/palliative systems, and academia to develop, implement, and evaluate PORT.

Research approach: Using a Participatory Action Research (PAR) approach, we collected demographic and service utilization data from PORT clients (n=92); carried out participant observation (~80 hours) at PORT development meetings, community activities, clinical rounds, and during direct client care; and conducted interviews (n=38) with PORT clinicians, clients, caregivers, and other service providers.

Relevance: In the first 25 months of the PORT service (July 2019-Aug 2021) PORT increased access to professional and informal care for underserved people, improved health outcomes, and reduced unplanned hospitalizations. The partnership and resultant service illustrated the value of relationship and collaboration, interdisciplinary teams, and intersectoral collaboration. Further partnership and investment is needed to support aging and death in place, and grief and bereavement support for caregivers, family, and workers in contexts of inequity.

Originality: This research stands as one of the few evaluations of an equity-oriented palliative care service.

Relevance to the conference theme: The creation of a multi-sector partnership between health/palliative care, social services, and academia to co-develop a community palliative service is a unique and innovative model to address SDOH and meet the needs of underserved populations, their caregivers, and communities.

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Developing patient-facing resources: Using co-design to create early palliative care tools

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Background: Research shows patients and families could benefit from an early palliative care approach along the illness journey. However, the label of palliative care remains stigmatized and scary for many patients. In collaboration with Health Canada, we embarked on a co-design process to develop tools that patients and families could use to help de-mystify an early palliative care approach without the labels, which will ultimately improve the illness experience.

Objectives/purpose: To share insights from co-designing four disease specific tools (roadmaps) designed to help achieve an early palliative care approach for patients and families diagnosed with Alzheimer's, Chronic Obstructive Pulmonary Disease (COPD), Amyotrophic lateral sclerosis (ALS), and Ovarian Cancer.

Research approach: Initial drafts of the roadmaps were created using background research and clinical knowledge from a palliative care specialist. We adopted a recruitment plan to obtain a wide variety of input from general practitioners, specialists, allied health practitioners, patients and family members. We completed two rounds of co-design sessions using two methods: individual qualitative interviews for the Alzheimer's and COPD prototypes and group qualitative interviews for the ALS and Ovarian cancer prototypes. We completed 11 individual interviews for the first round and two group interviews in the second round. We will describe the findings and learnings from both co-design processes and share final versions of the roadmaps.

Relevance: The codesign process revealed several insights into how patients and families wanted information early in an illness journey. It also showed how clinicians can use these tools in their practice to provide support for their patients. We will present the rationale for changes made, the learnings from our co-design process, and the final tools that resulted from the co-design feedback.

Originality: These roadmaps will be used by patients, families, clinicians and organizations to support those living with serious illness, particularly early in their illness journey. These Roadmaps offer accessible language and information to support patients and families in navigating their illness journey right from the time of diagnosis. Future steps include disseminating these tools through disease-specific organizations, and for free on our website, and completing user testing and evaluation.

Relevance to the conference theme: The co-design method used to develop these tools is relevant to the conference theme of community participation in palliative care. Attendees will learn about strategies used to include those with lived experience in the co-creation of tools from the start, as opposed to asking for their feedback once the product is already created, and how this will ultimately result in better uptake and spread from the disease community. This presentation will also discuss some initial results from user feedback to show how the roadmaps are being used in practice.

Palliative Care Is. . . A Collective Response to Death, Dying, and Grief in the Inner City

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Background/Context: In communities facing poverty, homelessness, racism, criminalization and toxic drug supply, there are urgent, unmet needs for palliative care and grief support. Workers in shelters, housing programs, drop-ins, and harm reduction settings often fill gaps in palliative care & health systems, and informal care. Despite their significant contributions, these workers are rarely formally recognized or resourced to address the complex care needs of the people they serve — or their own grief and loss. In these settings, staff turnover is high; medical leaves are common; and workers are left with complicated and disenfranchised grief.

Objectives/Purpose: To improve care for people living and dying in contexts of inequity and the experiences of those who support them, we formed an Action Team - composed of inner-city workers, palliative care practitioners, and researchers - to co-develop tools and strategies to embed a palliative approach to care in homelessness and harm reduction settings.

Over five years (2018-2023), the Action Team engaged in ongoing Participatory Action Research (PAR) and knowledge exchange. Workers' insights and experiences were merged with palliative care expertise to expose gaps, adapt tools, and develop practical strategies to better identify, engage, and support people who could benefit from a palliative approach to care. This process informed the creation of the Resource Guide, Palliative Care Is. . . A Collective Response to Death, Dying, and Grief in the Inner City, a seven-chapter, 90-page guide designed to support workers in providing care in these settings.

Relevance: The guide reframes palliative care as a collective response tailored to inner-city contexts. It contains co-developed adaptations to traditional palliative care tools (e.g., Advance Care Planning), making them applicable and actionable for homelessness and harm reduction settings. The guide recognizes grief as a natural response to loss, rather than pathologizing it as burnout or compassion fatigue, and it highlights the importance of workers' relationships and knowledge in facilitating care. By providing practical tools and building on existing care practices, the guide equips workers to reduce suffering and improve care in these settings.

Originality: This is the first resource to explicitly adapt a palliative approach to care for homelessness and harm reduction contexts using PAR methodology. It shifts the narrative from asking workers to "do more" to recognizing their essential contributions while equipping them with tools to meet better the needs of people living and dying in systemic inequity.

Relevance to the conference theme: This project exemplifies the principles of Public Health Palliative Care by integrating equity, community participation, and the social determinants of health into palliative care practices. It serves as an innovative model for transforming palliative care systems to be more inclusive, community-centered, and responsive to marginalized populations, advancing the conference's mission of fostering equity and justice in care.

Tattoos: Meaningful Stories

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Background: Tattoos can be seen everywhere in public, including on health care workers. However, scholarly literature on the subject is either mostly pathologizing or lacking.

Objectives: Our research program explored healing and memorial tattoos. We asked why people get tattoos and the meaning in the process, the design of the tattoos, and the bodily placement. Healing tattoos are defined as those that people obtain to celebrate, challenge, disrupt and/or (re)claim an aspect of themselves and/or of social phenomena. Memorial tattoos are those that honor someone who has died.

Research approach: This study involved a narrative inquiry design. Individuals with tattoos were interviewed using a semi-structured guide and photographs were taken of the tattoo(s). Interviews were audio recorded, transcribed, and analyzed thematically using continuing bonds, posttraumatic growth, and grief literacy as theoretical frameworks.

Relevance: Sixty-six people participated in interviews. Participants were eager to tell the story of their tattoos. Memorial tattoos help people maintain a connection to the person who had died. Healing tattoos assisted in posttraumatic growth by providing an intentional process of coping with stress. Both kinds challenged social stigmas about tattoos.

Originality: This research is innovative in that it addresses a phenomenon that is often seen in society but has warranted little research. The scholarly literature on tattoos mostly concerns dangers and deviance. This research is original in its positive approach to tattoos.

Relevance to conference theme: This program of research on tattoos has implications for all those involved in palliative care. Tattoos provide opportunities for health care practitioners to open conversations about the health and social history, and wellbeing of patients and families. Discussion of tattoos can represent invitations for connection on a deeper level by learning about significant experiences and meaningful relationships.

Not so fast - does the community want what you got? YES! Community engagement to improve a palliative approach to care for urban Inuit

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Background: Ottawa has the largest proportion of Inuit in southern Canada many of whom experience high rates of poverty, unemployment, vulnerable housing, and food insecurity. We wanted to know how these social determinants hinder access to health care and referral to palliative support and end of life care.

Purpose & research approach: Community engagement was undertaken in advance of a qualitative study using the Collaborative Research Framework (1) to better understand the experiences of urban Inuit in Ottawa facing homelessness or structural vulnerability when they need to access palliative and end of life care for themselves or for those they care for. We sought common ground and validation regarding whether the problem of culturally unsafe palliative and end of life care for urban Inuit in Ottawa resonated among urban Inuit community members.

Relevance: This presentation will describe the common ground seeking, mutual understanding and validation process that started in three community outreach gatherings held in the autumn of 2024 hosted by the research team and partner community organizations. The presentation will outline the content of the gatherings, trauma-informed and culturally safer considerations for community event planning and ongoing community participation.

Originality: We will underscore the ethical research design considerations in palliative care and end of life community partnerships, particularly culturally safer and trauma informed practices, assembling an advisory council, and navigating across organizational and interest-based communities within a community-partnered study.

Relevance to conference theme: We hope to share our experience in the crucial stage of community engagement in advance of a community partnered research project as a culturally safer practice in research on serious illness, caregiving, palliative care and end of life support and grieving.

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Advance care planning and structurally vulnerable populations: A scoping review of barriers, facilitators and interventions

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Background: Individuals living with structural vulnerabilities (SV) including homelessness, poverty, severe mental illness, substance use disorders, and racialization experience greater rates of serious illness. They also face obstacles to discussing their goals and values for future health care, termed advance care planning (ACP). There is interest in improving ACP rates for vulnerable populations as ACP improves quality of care and reduces unnecessary healthcare expenditure. However, evidence to understand relevant barriers and facilitators as well as to establish effective ACP interventions is largely fragmented.

Objectives: To review barriers and facilitators to ACP as well as ACP interventions in patients with SV to inform future ACP interventions.

Methods: We searched MEDLINE, Embase Cinahl and PsycInfo for studies dated between 2003 and October 2024. After removing duplicates, 2068 studies were screened and reviewed for a final article count of 70 studies. Extracted data was synthesized via content analysis to identify categories of barriers, facilitators, and targets of intervention divided into patient, systemic, and provider-related factors.

Findings: Thirteen barriers, thirteen facilitators, and six targets for ACP intervention were identified across a range of patient, systemic, and provider-related factors. Barriers and facilitators were frequently shared between different SV, suggesting common experiences and the potential for broadly applicable targets for improvement in vulnerable populations. Provider-level facilitators seemed to have the potential to impact barriers at multiple levels. Interventions to improve ACP were generally effective, with few exceptions. The most common interventions involved ACP education and outreach or guided ACP. Many patient-level barriers had mirroring patient-level facilitators without any interventions described in the literature, which suggests an interventional gap that may best be filled by close social supports.

Conclusion: Patients with SV experience many similar barriers and facilitators to ACP, which should be considered in ACP interventions for these patient groups. Interventions targeting ACP education and outreach or guided ACP are the most extensively researched and show promise in improving ACP for patients with SV if providers can incorporate ACP facilitators. Knowledge gaps may be present in targeting patient-level barriers with close social supports.

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Understanding barriers and facilitators to implementing a paramedic palliative referral pathway with people experiencing health and social inequities

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Context: When an ambulance is called for a person with advanced disease experiencing sudden and unexpected deterioration or exacerbation of symptoms, taking a patient to the emergency department is not always the right approach. Therefore, the BCEHS Assess, See, Treat and Refer (ASTaR) palliative referral pathway has been developed to allow paramedics to treat the patient in their home and connect them with appropriate community palliative services. While this pathway has demonstrated success in many settings, its implementation faces particular challenges in the contexts of health and social inequities.
Objectives: This study aimed to understand the experiences of paramedics in their use of the ASTaR palliative referral pathway in the context of health and social inequities, including the barriers and facilitators to its use.
Methods: We collected qualitative data from paramedics across British Columbia through an online survey and semi-structured interviews. Questions focused on paramedics' perspectives of the pathway's associated training and resources, their experiences of using the pathway in the context of health and social inequities, and any barriers or facilitators to using the pathway.
Findings: Key barriers include geographic and resource limitations in rural and remote areas, communication gaps between paramedics and other healthcare professionals, and challenges related to scope-of-practice constraints. Patient factors such as loneliness and compounded inequities, further complicate care delivery. Despite these challenges, paramedics demonstrated a strong commitment to patient-centered care and the value of the pathway. While many of the barriers relate to systemic-level issues, multiple actionable opportunities to enhance the pathway were identified, such as expanded awareness and training, and improved interprofessional collaboration.
Funding: This project received funding from the UBC SSRP program.

Adaptation of advance care planning public workshops for underserved populations

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Background: The principle of "accessibility for all" suggests that what's accessible for all improves everybody's lives. That inclusive design that addresses accessibility for some of the most vulnerable populations improves accessibility for everyone. We believe this principle can also be applied to the revision and adaptation of health service interventions, such as Advance Care Planning (ACP) education.
Objectives: In this presentation we will showcase how we tailored an existing training curriculum and toolkit that helps community non-profits host ACP workshop for the public by addressing the needs of specific populations, including the Chinese and South Asian Communities, and those affected by Dementia
Research approach: The adaptations to the toolkit were guided by effective public engagement and community participatory approaches. Throughout the adaptation and evaluation phases, we involved the population of interest and potential community organizations in multi-faceted ways across the public participation spectrum, from informing to collaborating.
Findings: Inclusion of members of the community is a key contributor to resource acceptability and uptake. When reviewing and updating materials, focusing on changes to account for health literacy and general cultural sensitivity, and adding more variety in the sample stories improve the materials for general users as well as the target populations. When conducting translations, use of translators with subject matter understanding with review by other bilingual team members with subject matter expertise facilitated translation that was culturally acceptable and addressed nuances of meaning.

Advancing advance care planning: A collaboration of health care, law, government, academia and the public - from incubation to action

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Although Canadians believe advance care planning (ACP) is important, just 17% have a plan. Researchers and practitioners advocate for multi-sectoral collaborations to address complex behaviours and processes and to improve public uptake. Lawyers routinely assist clients with ACP. Survey results show individuals want to receive information about ACP from lawyers, and lawyers want information about healthcare policies, a best practice guide and client worksheets.

To maximize the potential of ACP to improve quality of care, we implemented a medical-legal collaborative framework to jointly identify gaps, change professional practices, equip decision-makers, and roll out public education and resources.

In 2013, researchers began studying implementation of an ACP framework throughout this province's multisector system. It launched a collaboration of health, law, government, academia, and patient advocates to clarify legal and healthcare roles in ACP. A mixed methods approach (surveys, joint workshops, interviews, and literature reviews) was used to understand attitudes, barriers, needs, complaint trends, and practices.

Building on this foundation, we applied input from focus groups and a public panel to co-develop practice principles, a practice guide, and a course for lawyers, which were delivered and evaluated with the jurisdiction's legal education provider.

Our work exemplifies a multi-sectoral collaboration on ACP: we used data to prioritize activities and enlisted diverse, knowledgeable and influential stakeholders to optimize relevance and facilitate implementation.

Engagement confirmed the activities' relevance to stakeholders: 53 lawyers registered for the legal course and 26 participants from health (policy, practice), law (public, private), the Public Guardian, social work, and ethics co-drafted practice principles.

Evaluation results confirmed the course's quality and impact ("I can seriously improve my service to my clients"). It is accessible to 10,000 lawyers. Practical lessons include sustaining relationships with and between key stakeholders and tailoring approaches and messages to respective professions' concerns and cultures. Support for the collaboration's upcoming activities to further map out concrete solutions is strong.

Partnerships between health and law have been studied and implemented to address health inequities and gaps in policy and practice. Yet, their potential to improve ACP has been largely unexplored in Canada. We provide replicable processes, strategies and products to rollout partnerships, impact practice and support individuals' ACP.

This collaboration motivated the legal profession to improve alignment of their practices to clinical realities and equip their clients to act, fostering justice. Many of the collaborating agencies, such as the Public Guardian, public legal education and legal assistance, are concerned with equity, access, and services for vulnerable people. They have co-presented and provided advice, content, and cross-promotion for education and tools for the public, legal and medical communities.

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Validation practice in the clinical applications of quality-of-life assessment tools in palliative care

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Quality-of-life (QoL) assessment tools, such as patient-reported outcome measures (PROMs) are increasingly used in palliative care (PC) to reflect patients' voices. Contemporary measurement validity theories suggest that validation practice involves accumulating and synthesizing evidence to support interpretations and actions based on measurement scores. Measurement validity theories have been developed more often for psychometric purposes, including aggregate-level interpretations of scores, in education and psychology. Therefore, a knowledge gap exists for the clinical applications of QoL assessment tools, including in palliative care. The study aimed to understand how patients and PC professionals enacted validation practice in the clinical applications of QoL assessment tools in PC. Using an interpretive description approach, we observed participants using QoL assessment tools during routine care, and we individually interviewed eight patients living at home with life-threatening illnesses and six PC professionals. The data were analyzed diffractively to tell parts of a story about validation practice in the clinical applications of QoL assessment tools in palliative care. Validation practice is not a homogeneous phenomenon. Validation practices can be enacted by the relational use of QoL assessment tools; by focusing on an ongoing reflective dialectical interpretation of the scores with patients; by ascertaining with patients which priorities are most important to them; by skillfully using relevant metaphors to recognize the patient as a person; and by asking further questions to determine the patient's goals of care. As a boundary object with agency, a QoL assessment tool collaborates with people to create practice-based validity evidence. Diffractive analysis of socio-material practices enabled the observation of interference patterns and the consequences of using these tools. Better population health outcomes require information reported directly from patients. Without a person-centred approach to using QoL assessment tools in palliative care, professionals risk intervening (or not intervening) based on assumptions rather than justifications.

Extending aging in place to dying in place: The role of collective occupation and place-making in palliative care

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Background: Aging in place has been widely explored in research and policy, yet the transition from aging in place to *dying in place* remains underexamined. "Place" encompasses more than just a physical location; it is actively shaped by people's occupations—the everyday, meaningful activities individuals engage in independently or collectively (WFOT, 2022)—as well as their relationships and lived experiences. An occupational perspective provides valuable insights into how older adults cultivate belonging and well-being throughout their lives, including at the end of life. As palliative care increasingly embraces person-centered and culturally responsive approaches, it is essential to recognize how place and occupation can support dying in place.

Objectives: This study explores how older adults engage in collective occupations to create meaningful places of belonging and how these processes inform palliative and end-of-life care. Drawing on research on Naturally Occurring Retirement Communities (NORCs) and digital storytelling, this work seeks to expand the understanding of aging in place by examining how place-based activities influence well-being until the end of life.

Research approach: This study adopts a qualitative approach informed by an occupational science perspective to examine older adult's experiences. It integrates findings from three sources: a scoping review on place-making among older adults, a qualitative descriptive study on their collective occupation in NORCs, and insights from digital storytelling. By analyzing the lived experiences of older adults across these sources, this study explores how collective occupations promote continuity, connection, and wellbeing in later life and at the end of life.

Relevance: This work advances our understanding of palliative care by emphasizing the importance of place and collective occupation. It shifts the perspective from medicalized understandings of end-of-life care to one that incorporates meaning, belonging, and lived experience. This study contributes to innovative, person-centered approaches that improve the quality of life until death. Additionally, it provides insights for community-based and Indigenous palliative care education, highlighting the need for culturally safe, socially connected care environments.

Originality: By bridging research in aging, occupational science, and palliative care, this study introduces a novel framework for understanding dying in place. It underscores the role of occupations in fostering place attachment and social participation, particularly in community-driven palliative care models.

Relevance to conference theme: This study aligns with themes of *Community Participation in Palliative Care* and *Addressing Social Determinants of Health in Palliative Care*. It calls for an expanded approach to aging and dying in place—one that values the occupations and relationships shaping meaningful experiences of living and dying. By integrating research and practice, this work provides a foundation for innovative, community-based palliative care approaches that honour individuals' connections to place and occupation throughout their lifespan.

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Nursing in a Compassionate Community

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Background: Community participation in the implementation of Compassionate Communities and Cities is essential to build community capacity to support individuals living with chronic, progressive, and serious illness. However, it has been identified in the literature that there is a need for healthcare professionals to engage in leadership and championing of Compassionate Community and City development (Abel et al, 2018; Librada-Flores et al, 2018; Matthiesen et al, 2014). Nurses' education and experience uniquely positions them to be strong partners in the implementation of Compassionate Communities and Cities. Nurses have long been at the forefront of health promotion work and advancing equity.

Objectives: The aim of this study was to describe and understand the different ways that nurses engage in the planning and implementation of Compassionate Communities and Cities in Canada.

Research approach: The principles of interpretive description (Thorne, 2016) were used to guide this study. Data was generated through semi-structured interviews on Zoom and analyzed using thematic analysis (Braune & Clarke, 2006).

Relevance: Nurses assume three roles in the planning and implementation of Compassionate Communities and Cities: 1) catalysts to move initiatives forward, 2) health promoters, and 3) bridges between individuals, community partners, researchers, and the healthcare system. The participants also discussed the importance of integrating the public health approach to palliative care across the healthcare system and provided recommendations for nursing education to prepare nurses for this role. Nurses have a key role in promoting uptake and implementation of Compassionate Communities and Cities to increase equity, inclusion, and public participation in palliative care.

Originality: This is the first study to explore the nursing role in implementing Compassionate Communities and Cities.

Relevance to conference theme: The principles of equity and inclusion and promoting palliative care practices that are community and citizen centered are embedded throughout this study.

Measuring death literacy and death anxiety among college students: A mixed-methods, compassionate cities approach

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Background: Death literacy is defined as the knowledge and skills needed to access, understand, and act upon end-of-life care options, and plays a critical role in fostering the ability of communities to care for its members. Post-secondary students represent a critical yet underutilized demographic in these efforts. Furthermore, research highlights a strong relationship between death-avoidant behaviors and a lack of education on death and dying, negatively impacting students' preparedness to engage with dying individuals and their families in both personal and professional contexts.

Purpose: To purpose of this study was to assess the death literacy and death anxiety levels of students enrolled in a post-secondary institution in Southern Ontario.

Research approach: Informed by a compassionate communities framework, this study employed a mixed-methods approach to address the following research question: What are the levels of death literacy and death anxiety among college students? In 2024, an online, campus-wide survey was administered to a representative sample (N=376) and included the Death Literacy Index, Templer's Death Anxiety Scale, short answer questions (e.g. do you have experience volunteering/working in a palliative-related field?), and demographic questions.

Findings: The average age of participants was 26 (range: 18-64), with 23% already providing care to an older family member. Findings revealed high death anxiety and low death literacy: 71% feared dying a painful death, 65% lacked confidence in completing end-of-life planning, and 41% lacked access to culturally appropriate caregiving resources. Findings highlight the need to identify opportunities to address death literacy across the age continuum in academic settings. Steps to address these findings in the form of targeted on-campus workshops will be shared in this presentation.

Relevance and originality: By framing death as a shared community responsibility, this approach supports public health palliative care goals of improving accessibility, equity, and quality of care, fostering a culture of empathy and preparedness among future caregivers. By identifying key barriers and opportunities, the research aimed to inform the development of educational interventions to equip students with the skills and knowledge necessary to contribute to compassionate, community-oriented ecosystems.

Funding: Fanshawe College, Surge Innovation Grant

Enhancing death dialogues using No Barriers Here: An arts-based methodology to advance care planning with college students

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Background: While end-of-life/advance care planning is usually seen as an activity undertaken by health care providers working in specific areas of the health care sector (e.g., hospice and palliative care), over the last decade doulas have come to the forefront to take up this work within community settings, Relatedly, 8 in 10 Canadians think more acceptance around talking about sickness and death in our society is needed, it has also been reported that more resources and support are needed to encourage people to engage in such conversations.

Death literacy is defined as the knowledge and skills to understand and act on end-of-life care options, critical for informed decision-making, and yet remains low among many populations. Authors' conducted a campus-wide survey to college students (N= 378), which demonstrated: 71% feared death, 65% lacked confidence in completing end-of-life documents, and 61% were unsure how to navigate the healthcare system to support a dying individual. Existing research, while sparse, demonstrates that undergraduate students benefit from opportunities to engage openly about end of life.

Purpose: Based on survey findings, we adopted the innovative *No Barriers Here* arts-based approach to be appropriate and deliverable to students in 2-hour workshops facilitated by doula faculty. This study explored how these arts-based workshops engaged students in end-of-life planning, enhanced their death literacy, and reduced death anxiety.

Research approach: On-campus workshops were co-facilitated by doulas and community partners, trained in *No Barriers Here* methods, and involved students from various programs across a college in Southern Ontario. Participant observations were documented, and with participant consent, photographs of created artifacts were taken. Group discussions were digitally recorded to capture participants' reflections on workshop content and process, and subsequently thematically analyzed.

Key findings: Ten workshops were delivered to a total of 70 participants, with representation from across the college. Workshop participants reported that engaging in arts-based activities reduced stigma and fear surrounding death, increased their confidence in end-of-life planning, and encouraged them to open dialogue with their own family and friends. Students found the workshops valuable for reflecting on their personal and professional roles in caregiving.

Relevance and originality: By integrating end-of-life discussions into academic settings, the adapted *No Barriers Here* methodology invited students to safely address death-related fears and consider their options at the end of life. Such innovative approaches serve as an exemplar of how death education can be made accessible and is aligned with a public health approach to equity-oriented advance care planning.

Establishing definitions and indications of integrated palliative care across specialties treating non-cancer illness: A study in progress

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Background: To meet population needs for palliative care of non-cancer illness, a palliative approach must be integrated into all relevant settings and medical specialties. The implementation and measurement of this integrated palliative approach are underdeveloped.

Objective: To describe the extent to which a palliative approach is occurring using health administrative data. As a first step, we are exploring how to adapt definitions and algorithms for health administrative data to capture non-cancer patient populations and health care activities that reflect integrated palliative care.

Approach: Key informant interviews are being conducted with primary care, palliative care, other specialist physicians, and knowledge users. We will present disease definitions and approaches to measuring palliative care using administrative data, for feedback on how representative these are of integrated palliative care, and whether specific physician and patient populations are characterized appropriately. We will analyze the content of conversations to identify how to capture relevant populations and palliative approaches for different specialties.

Results: We anticipate guidance on characterizing appropriate patients (e.g., those with an indicator of disease progression) and providers (e.g., cardiologists with a focus on heart failure, comprehensive family physicians) where a palliative approach to care would be applicable. Key index health events and treatments will be identified. Furthermore, inflection points in management that could signal a shift to a palliative approach will be identified.

Relevance: This phase of the study will enable optimal use of health administrative data, to ultimately create knowledge products that have the potential to influence primary care and specialist health professional organizations.

Originality: This research focuses on improving equity in access to palliative care and achieving earlier integrated palliative care in the community.

Evaluation of a brief social health screener to increase support seeking behaviour: An opportunity for people living with serious illness and their caregivers

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Background: Social health refers to the overall well-being and functioning of individuals within their social relationships, communities and is related to life satisfaction. People experiencing serious illness and at the end of life and their caregivers are at risk of becoming disconnected from networks and experiencing inadequate practical and social support for quality of life. We developed a short 'Social Screener' as a free web-based tool that helps individuals identify social health risks. After completion, users receive a personalized report with feedback to take steps to improve their well-being, leveraging informal and community networks.

Objective: To field test and explore the HWFC Social Screener's feasibility, usability and perceived impacts.

Research approach: The prototype screener was introduced to diverse participants through an existing community support service client base and student intern programs. Interviews were completed to gather feedback on usability and usefulness of the risk information and feedback report.

Results: Twenty-five individuals participated. Most participants were female (76%) and 32% were aged 60 years and older. Forty percent of participants were identified as moderate to high on social risks. Participants appreciated the structured approach to assessing social well-being and the relevance of the information. User friendliness was noted across participants of all socio-economic backgrounds. Usefulness themes were: new knowledge, self-awareness, behaviour change, social activities, re-connecting, neighbourhood and community and healthy habits.

Relevance: The screener and report recommendations were feasible to use and identified strategies seen to be instrumental in initiating positive changes in support-seeking activities.

Originality: This novel approach to social screening could be a useful addition to service provider tools to highlight patient needs and informal networks available.

Advancing the methodology behind arts-based knowledge translation of palliative care research: Collaborating with artists and designers to develop knowledge products

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Background: Research findings are not always accessible to the public, and some people may not think research is "relevant" to them. Traditional knowledge translation (e.g., academic articles) reaches a select audience. Arts-based knowledge translation (ABKT) can reach a broader audience and have a wider impact. ABKT can also support data collection, recruitment, and contextualization of research.
Objectives: Our poster will present our unique and innovative approach to ABKT in palliative care research and empower others to use this approach.
Research approach: Our research-to-public-to-research feedback loop approach leverages research findings to inform the art/design output, then uses the output to collect information from viewers. We then synthesize the viewers' contributions to inform research. Our poster will:

- Describe the history of ABKT and share the details of our approach.
- Review two exemplar palliative care installations (Going Home to Die, and the Terminal Diner) and their findings.
- Provide lessons learned and tips on how to: obtain funding, use co-design to develop an installation, navigate securing venues, promote the work, and approach copyright considerations.

Relevance: This work will advance attendees' ability to increase interactions between researchers and the public thereby increasing relevance and impact of research.
Originality: Our work connects people from all backgrounds to research through art and design, which makes the research engaging and personal for them. This novel approach is innovative in palliative care research, but also the broader health services research space.
Relevance to conference theme: Our approach to ABKT broadens public access and engagement. By making palliative care research more accessible and engaging for diverse audiences, this approach aligns with the theme of fostering dialogue and action for underserved communities.
Funding: This work was funded by CIHR.

Creating inclusive research practice - The development of the C-CARE Methodology

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Background: Research practice which aims to address inequities in palliative care, and wider healthcare, often adopts participatory methods which aim to centre lived experience. Coproduction and cocreation are terms widely used in research but often lack robustness and authenticity. Similarly, there has been an increase in the use of arts-based methods in recent years, but with a lack of clarity about how participant created images are analysed, this important less-verbal data is often reduced to spoken word. Both coproduction and arts-based approaches have the potential to create more inclusive research practice, but there is a need for further methodological developments to ensure their meaningful and appropriate use.

The author has developed the C-CARE methodology through an equity-oriented, arts-based approach to advance care planning with communities often underserved in palliative care. Through development of an intervention, inclusive research practice was developed, refined and coproduced. This paper presents the C-CARE methodology and highlights its potential wider use in equity-oriented research practice.
Objectives: Alongside to the development of an advance care planning intervention, the authors aimed to develop a methodology which supported equitable delivery of and participation in palliative care research.

Through three research studies exploring the needs of different groups and communities and the development of an education programme for healthcare professionals, a research methodology was developed which aims to address the need for effective, meaningful coproduction and which was inclusive and safe for participants, which disrupted traditional power dynamics in the researcher/participant relationship.
Research approach: Research questions related to the group or community the study focused on thematic and methodological questions. Each study had a coproduction steering group which not only oversaw the study from a thematic perspective, but also in developing and refining the research approach.

The C-CARE Methodology: **C**ommunity Engagement, **C**oproduction, **A**rts-based methods, Inclusive **R**esearch Practice and **E**ducation.

Our approach was iterative, with learning from each stage incorporated into the final model. For example, community engagement became an essential stage to support meaningful coproduction. Our commitment to authentic coproduction led to the use of inclusive research practices such as coproduced data analysis, delivery of education sessions by people with lived experience and co-authoring publications with coproduction group members with lived experience. Examples will be included in the presentation of the paper.

Relevance: This paper will present the C-CARE methodology, outline its development, its grounding in equity-oriented palliative care research and highlight its potential use in wider health inequalities research.

Originality: C-CARE is a novel methodology. The author encourages other researchers to adopt the C-CARE approach and support its future evolution.

Relevance to conference theme: The C-CARE model offers the conference a novel methodology for health research through a participatory, equity-oriented lens which the author believes will be of interest.

Conveying indirectness and politeness: Mitigation usage by Chinese immigrant patients, their caregivers, and palliative care clinicians

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Background: Studies of Chinese immigrant patients' and caregivers' experience with advance care planning consistently demonstrate a preference for indirect communication. Mitigation devices are examples of intended indirect speech (e.g., *shields, hedges, bushes, etc.)* that reduce unwelcoming effects on the hearer.

Aim/research question or hypothesis: Our study examines the prevalence and predictors of mitigation devices during inpatient palliative care (PC) consultations with Chinese immigrant patients.

Methods: This is an analysis of consultations between PC physicians, adult Chinese immigrant inpatients, and caregivers at a tertiary academic hospital in Toronto, Canada. We consecutively-recruited eligible participants from September 2022 to September 2023. We obtained participant sociodemographics and clinical characteristics using structured surveys. We used framework analysis at the sentence level to identify mitigation devices in PC consultation transcripts. We descriptively analyzed the frequency, type and distribution of mitigation devices.

Results: We analyzed ten unique PC consults. Patients had a mean age of 72.1+/-18.5 years; 60% were female and 50% were Mandarin-speaking. Patients had a median PPS of 40[40-60] and 90% had a cancer diagnosis. Of the 5522 total sentences, 1032 (18.7%) contained a mitigation device. The most common mitigation devices were *hedges* (64.7%), *bushes* (18.3%), and *tag questions* (7.0%). Physician sentences were more likely to contain mitigation devices than patients' (OR=1.4, 95%CI:1.2-1.6) or caregivers' (OR=2.3, 95%CI=2.0-2.8) sentences. Among sentences containing mitigation devices and compared to English sentences, Mandarin sentences were more likely to contain *shields* (OR=7.3, 95%CI:3.3-16.1), and less likely to contain *hedges* (OR=0.2, 95%CI:0.2-0.3), *parenthetical verbs* (OR=0.2, 95%CI:0.1-0.4), and *tag questions* (OR=0.5, 95%CI:0.3-0.8).

Discussion: During inpatient PC consultations with Chinese immigrant patients and their families, physicians' speech is more likely to contain mitigation devices than patients' and caregivers'. Language also predicted the type of mitigation devices used. Further work is needed to understand the impact of service language choice and mitigation devices on the experience and patient-oriented outcomes of PC consultations.

Grief Matters: Making space for grief in public health palliative care

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Background: Public health palliative care (PHPC) has made important strides towards advancing research and practice about mortality and loss. We are concerned, however, that to date the focus has been more on mortality than it has been on loss.

A key tenet of PHPC is that people with terminal illness spend about 5% of their time with medical specialists; 95% is spent with family and friends in their communities (Kellehear, 2022). What about those who remain after the death; what about the grief that people carry that extends well beyond palliative care? While the Public Health Model of Bereavement Support (Aoun et al., 2015) starts to capture the supports needed after a death, grief is bigger than bereavement; it is an embodied, multidimensional response to any kind of loss.

100% of people in the triangle can benefit from improved grief literacy.

Purpose and approach: We believe PHPC research and practice needs to open more room for grief. We created Grief Matters, a Canadian non-profit that aims to facilitate grief literacy on a national scale. An example of the work that we do is to crowd-source events that we call 'Grief Gatherings.' We have supported over 80 events, hosted by individuals, community organizations, health care institutions, faith-based organizations, and research teams. Grief

Gatherings embrace the tenets of grief literacy in that they are tailored to different ages, communities, genders, physical abilities, sexualities, incomes, geographic locations, and include a range of griefs. Our website includes monthly blog posts and cartoons by our team and guests. We have a newsletter and are actively creating partnerships with other grief related organizations.

Relevance and originality: There are positive public health ramifications when communities come together to talk about grief. Talking about grief decreases stigma and loneliness. Grief Matters strives to be an open platform to debate critical questions, share evidence of change, and take action to transform the way we care for grievers in our communities.

Grief Matters is inspiring community members to grow grief literacy. We can all contribute to the revolution: in our own neighborhoods or on a national or international scale. It all matters.

Engaging young people in end-of-life policy: A national study

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Background: In Canada, children and youth (‘young people’) remain excluded from policy development processes, including those related to palliative end-of-life (P-EOL) care, and Medical Assistance in Dying (MAID). This exclusion is an inequity and contravenes the spirit of the UN Convention on the Rights of the Child. Significant gaps exist in understanding how young people experience and engage with P-EOL care. Our three-year national study seeks to address these gaps by working with young people and their care partners to generate evidence that can inform policy and practice for pediatric P-EOL, including MAID for mature minors.

Purpose: This study explores the perspectives of young people and their care partners on P-EOL care. By centering youth voices, this research aims to contribute to policy discussions and decision-making processes that directly impact young people. The overarching goal is to ensure that young people’s rights, capacities, and experiences inform P-EOL care policies in a meaningful, inclusive, and just way.

Approach: Phase One (underway) involves participatory engagement with youth advisory councils and clinician advisors to define the research design, methodologies, and analytical approaches for subsequent phases. Phase Two will involve primary data generation through focus groups, interviews, and art-based methods, engaging young people, parents, care partners, and clinicians. The analysis will be guided by a childhood ethics framework, which recognizes young people as agents with the right to participate in matters affecting them. Final methodological decisions will be made in collaboration with youth and clinician partners to ensure alignment with their needs and priorities.

Relevance: This study has significant implications for knowledge advancement, clinical practice, and policy development. Research shows that involving patients and families in decision-making around P-EOL care leads to better experiences, ensuring care aligns with their values, preferences, and needs. By engaging young people in shaping policy, this work contributes to developing more responsive and inclusive healthcare practices that reflect the realities and priorities of young people and their families.

Originality: This is the first national study to engage young people as active partners in policy-making about their own P-EOL care. It challenges prevailing assumptions that exclude children from these discussions and employs participatory methodologies to amplify youth perspectives. The study also integrates innovative approaches, including arts-based methods, to generate diverse forms of knowledge that can inform policy and practice.

Relevance to conference: This study aligns with the principles of public health palliative care by prioritizing inclusion, equity, and community engagement. By positioning young people at the center of discussions, it contributes to a more just and participatory approach to pediatric P-EOL care policy and practice in Canada.

Funding: This project is funded by Health Canada; the views expressed herein do not represent the views of Health Canada.

Honohono Tātou Katoa / Creating Compassionate Communities from the inside out

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Background: Following the 6th Public Health Palliative Care International Conference in Australia in 2019, it became apparent that despite our hospice’s community grassroots origins in the 1970s, we had evolved to align with the dominant Western way of providing healthcare. Our referral-based service of specialist palliative care was exclusive. We did not know our community well enough to know who we were missing out. A public health approach to palliative care offered a way to redress this.

Objectives: In January 2023 we embarked on a three-year feasibility initiative to implement public health palliative care in, and from within, an urban hospice - that is, doing this from the inside-out and turning things upside-down.

Research approach: We describe what we have done. We share who we are, why we did it, how we did it and what happened. Through a QR code we describe the team composition, budget, timeline, funding, accountability, challenges, celebrations, resources and more.

Relevance: This experience is relevant to organisations that wish to consider complementing a referral-based service with a public health approach in palliative care. This is a significant paradigm shift to '. . *.view the community as an equal partner in the long and complex task of providing quality healthcare at the end of life'* [Public Health Palliative Care International]. By being inclusive of all communities, this approach counterbalances the exclusivity of referral-based palliative care services.

Originality: There is scant guidance on how a hospice might 'do' public health palliative care. We describe our experience.

Relevance to conference theme: The innovation in caring is to explore how to counterbalance the exclusivity of referral-based palliative care services by integrating a population, community-informed, way of working (the public health palliative care approach). We describe the action, what we have done (and are still doing), to achieve this.

Grieving in the time of the opioid crisis: A look at how the inclusion of a palliative care lens could better support youth on their grief journey

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Background: Death is a universally experienced life event; however, grief, loss, and bereavement are not experienced equitably across populations. Grief, which encompasses bereavement and other experiences of loss, is often understood as an individual experience, leaving the broader social contexts within which death and dying occur under-examined. There is little known about the grief experience for youth who are street-involved (YWSI) and what their wants and needs are to move through their life in an equitable and safe way.

Objectives/purpose: The purpose of this research is to: (1) Provide a detailed description of grief and loss for youth who are street involved (YWSI); (2) examine the social, historical, and political contexts within which YWSI are situated; (3) Generate evidence to inform educators, care providers, support workers, and caregivers to create more equitable responses to enable grief support for YWSI. Please note that this project is still underway but will be finished at the time of the conference.

Research approach: Following Interpretive Description, guided by community-based participatory research methods, author is meeting with youth, aged 16 - 19 years of age, multiple times over a few months for semi-structured interviews and observations (n=6). Additionally, interviews are being conducted with practitioners (n=5) involved in care of YWSI.

Relevance: This project aims to fill the gap to build knowledge and understandings of how to create more equitable programs for youth whose grief in often invisible and not well understood. This knowledge is imperative if we are to better support YWSI within our communities as they are some of the most vulnerable in our society.

Originality: This study is an original contribution to knowledge in palliative care.

Relevance to the conference theme: This research aligns with the conference's focus on community participation in palliative care by including YWSI in the discussion around their own care and support needs in the context of grief care during a toxic drug crisis.

Funding source: SSHRC Canada Graduate Scholarship Masters

Implementation of a Patient Navigator into the National Cervical Cancer Screening Program in Tanzania: Promoting upstream approaches to ensure appropriate treatment and care, including palliative care for advanced disease

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Introduction: Deaths from cervical cancer (CC) are disproportionately higher in low and lower middle-income countries (LMICs). In Tanzania, CC is the most common cancer among women living with HIV (WLHIV) and the leading cause of cancer-related death for women. CC is the first cancer preventable by vaccination, and for which a global elimination strategy has been developed by the WHO. The WHO 90/70/90 Elimination targets are '90% treatment and care for pre-cancerous lesions and cervical cancer cases' and include strategies to strengthen and integrate palliative care services.

Previous research at Tanga Regional Referral Hospital (TRRH) in Tanzania evaluated 'most responsible diagnosis' for women registering for palliative care. Cervical cancer represented 60% of all responsible cancer diagnoses in women, and 30% of all age female deaths (2013/14 data). Subsequently, Cervical Cancer Screening (CCS) was introduced at TRRH in 2016 and subsequently established throughout the Tanga Region.

Global health literature has focused on the efficacy of single-visit CCS programs in LMICs, with few studies providing a longitudinal assessment of the overall CC care cascade that follows from a positive result. At TRRH, the "Tanga Dataset" was developed to describe the screening outcomes of the first 3 years of CCS, and measure women's engagement with the prescribed treatment cascade. Results of this research demonstrated a large burden of CC and pre-cancers, but also significant rates of loss-to-follow up (LTF) identified for women needing diagnosis via biopsy, access to their results, and referrals for cancer and pre-cancer care. Linkages between screening and treatment are underdeveloped, including access to palliative care (PC) for women presenting with advanced disease.

Relevance: Cervical cancer screening will require a matching increase in capacity for treatment of the detected lesions as screening women without access to treatment is unethical (WHO). Observational narratives from providers at TRRH note that many women present for screening and care because they already have symptoms of advanced incurable CC. Measuring access to PC is as important as measuring engagement in preventative and curative care especially during early years of screening uptake in Tanzania.

Objectives: 1. Evaluation of a Cervix Disease Navigator (CDN) implementation strategy to decrease LTF, and support women identified with cervix disease to access their prescribed care cascade, including PC for advanced disease.

2. Collect data about barriers and enablers for women to engage with the care cascade.

Methodology: A Type 2 hybrid effectiveness-implementation mixed-methods observational study design will be used to assess the feasibility, acceptability and costs of implementing a CDN role to facilitate linkages from screening to treatment including palliative care. Funding from private donor.

Building a more equitable and inclusive practice: From refugee to palliative care champion - A journey of identity and advocacy

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This poster outlines a framework for healthcare providers to examine how their personal identities and experiences shape their practice, with the goal of creating more equitable care.

Core Concept: The central wheel diagram maps various social identity categories (ethnicity, age, gender, socioeconomic status, etc.) that intersect to form an individual's unique social location. This positioning determines one's experiences of power, privilege, or disadvantage across different contexts.

Key Learning Components:

Self-Awareness: The framework emphasizes identifying privilege within disadvantage - recognizing that individuals can simultaneously hold advantaged and disadvantaged positions depending on context.

Learning Moments: Four critical areas for professional development:

- Making meaning from past experiences
- Understanding systemic barriers
- Developing cultural humility (acknowledging limitations, being open to learning from others)
- Engaging in humanitarian efforts and advocacy

Practical Application: The poster includes reflection questions like "What do I need to learn from you so I can support you better?" - moving beyond assumptions toward genuine inquiry about patient needs.

Theoretical Foundation: Draws from intersectionality theory and cultural humility frameworks, connecting personal narrative (refugee experience) with professional healthcare practice.

The poster creates space for collective knowledge-sharing that challenges traditional power dynamics in healthcare, while providing practical frameworks for incorporating social justice principles into daily practice.

Essentially, it's a structured approach for healthcare providers to engage in critical self-reflection and identify areas where unconscious bias or assumptions may influence patient care - enabling more intentional, equitable practice.

Towards a scalable health system approach to advance serious illness communication, training and implementation

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Background: Serious illness conversations (SIC) promote prognostic awareness and align care with patients' goals and values, improving patients' well-being. The Serious Illness Conversation Guide (SICG) is a structured tool used to train clinicians via in-person training. Instructors' and trainees' time commitment and scheduling logistics pose training challenges. This randomized controlled trial (RCT) assesses if Virtual Reality (VR) is a viable alternative to deliver SICG training.

Objectives: This pilot RCT aims to assess the feasibility and effectiveness of VR training compared to in-person training, to guide planning of a future larger non-inferiority RCT and to identify factors that predict/inhibit uptake and documentation of SIC among cancer clinicians.

Approach: Quantitative and qualitative data are analyzed from the training of 48 oncology physicians through in-person or VR sessions, using a convergent mixed-methods approach. Outcome measures including study enrollment and completion rates, training adherence and acceptability rates and time required for data collection are collected to assess feasibility. Other study outcomes include pre-post reports of clinicians' skills and confidence, training satisfaction score, presence of documentation of SIC following the training, and quality of documentation. To guide a larger non-inferiority RCT, effect sizes and uncertainty intervals of potential primary outcomes are analyzed. Finally, a multidisciplinary sample of cancer clinicians is interviewed to elicit their perspectives on the facilitators, barriers, and outcomes related to SIC. Interpretive description is used as a methodology to generate knowledge useful for practice.

Relevance: We hypothesize that VR training is feasible and accepted, and that the preliminary data provides sufficient guidance for a larger RCT. This study may provide an unprecedented opportunity to upscale communication skills training using VR as an effective alternative, meeting the needs of busy clinicians in diverse practice settings.

Originality: This is an original RCT.

Relevance to conference theme: This study explores VR technology as an innovative method to train clinicians in SICG, optimizing the delivery of personalized and culturally-safe care to underserved populations, ensuring equitable access to care.

Funding: Rossy Cancer Network (Cancer Care Quality & Innovation Program Research Fund)

Implementation of a data-enabled cancer care delivery model to provide timely, precise and equitable referrals to supportive and palliative care services

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Background: People affected by cancer commonly experience significant distress related to their diagnosis, treatment, and prognosis. Despite guidelines recommending early integration of supportive and palliative care (SPC) services, referrals are often delayed and imprecise. Furthermore, inequities in care for marginalized individuals are difficult to address due to gaps in collecting social determinants of health (SDH) data. Artificial intelligence (AI) may mitigate referral challenges by quickly and accurately summarizing data related to palliative care need for referring healthcare providers.

Objective: To assess the feasibility and acceptability of an AI-enhanced cancer care delivery model designed to improve the timeliness, precision, and equity of SPC referrals.

Research approach: We will use the Consolidated Framework for Implementation Research within a Living Lab model to conduct an iterative, exploratory study at our cancer centre. We will recruit 400 adult patients with pancreatic, lung, or colorectal cancer; collect SDH data from all patients and 6-weekly patient-reported outcome measure (PROM) surveys from 75 pancreatic cancer patients. Using a local, secure large language model, we will generate summaries of these data for referring providers. We will conduct qualitative interviews to explore patient and provider perspectives on these processes, and exploratory quantitative analysis to investigate associations between PROM and SDH data.

Relevance: This project addresses the critical need for timely and equitable SPC referrals.

Originality: The integration of AI, PROMs, and SDH data in cancer care delivery is a novel approach to personalized and equitable SPC.

Relevance to conference theme: This project centrally involves innovative technology.

Expected outcomes: Preliminary data to inform a larger clinical trial; enhanced data collection, analysis, and utilization; improved timeliness, precision, and equity of SPC referrals; improved patient experience.

Using a train-the-trainer model and community partnerships to offer "Palliative Care Education for Everyone"

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Background: A premise of the Compassionate Communities movement is that everyone has a role in supporting the people around them who are seriously ill, dying, caregiving and grieving. Yet many lack the confidence and knowledge to do so. Equipping community members to play an active role during sickness, dying and grief can better support those going through these experiences, reduce the burden on primary caregivers, and provide opportunities for meaningful social connection.

Objectives: To nurture Compassionate Communities by adapting an innovative palliative care public education program to the local context, training local facilitators in communities across one Canadian province, and hosting courses for the public in partnership with a range of community organizations.

Research approach: To address a gap within existing palliative care public education, we adapted four PalliLearn courses developed in Australia for public audiences. We used a train-the-trainer model to scale and spread the PalliLearn series to local communities across our province. Facilitators are required to be health professionals with palliative care experience, and to deliver the courses at no cost in their communities. To date, 24 facilitators from across the province have completed facilitator training. Online and in person courses have been hosted for the public by a range of community organizations, including hospice/palliative care societies, public libraries, senior-serving and caregiver organizations. Participant evaluations indicate high satisfaction with the courses and demand is growing for facilitators to deliver courses in partnership with host organizations.

Relevance: The design and implementation of this educational curriculum provides significant opportunities for learning about how best to support and engage: (i) the public as learners; (ii) clinicians as educators; and (iii) community organizations as hosts. As palliative care organizations and health systems work to strengthen health literacy and nurture supportive community networks, these learnings may have broad applicability to conference participants.

Originality: Our goal to proactively equip the public with information before they need it is a departure from typical reactive approaches. The series itself is original in providing easy to understand, engaging education designed for public audiences about palliative care and related topics. Additionally, our organization uniquely connects clinicians with community organizations in the non-profit sector to engage with the public beyond the health system.

Relevance to conference theme: The PalliLearn education program proactively equips the public with information through free and accessible public education sessions. This educational series encourages community involvement in palliative care and aims to break down some of the barriers to equitable access to palliative care arising from lack of awareness or misinformation about palliative care. In the implementation of this public education program, engagement with diverse community organizations has been undertaken to reach a broad public, including underserved communities.

Funding: Government of Alberta.

Design elements implemented within palliative care and hospice units: A scoping review

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Background: The ways physical healthcare spaces influence users' (e.g., healthcare providers, patients, family caregivers) experiences has been examined in environmental psychology, hospital design, and architecture literature. Intentionally designed healthcare environments have been studied in acute care and long-term care units; however, a synthesis of knowledge about palliative care and hospice units is lacking.

Objectives: Our scoping review explored the design elements or interventions that have been implemented in inpatient palliative care and hospice units.

Research approach: We searched six databases (MEDLINE, Embase, APA PsycInfo, CINAHL, AARP AgeLine, and Scopus) using a peer reviewed search strategy. Search terms included keywords related to palliative settings, built environments, and wellbeing. We identified 11,974 articles. After removal of duplicates, we screened 6129 titles and abstracts. We then screened 52 full text articles. Three articles met inclusion criteria.

Relevance: Included studies were conducted in Belgium, Australia, and Canada between 2018-2023. Design elements in palliative care and hospice units were facility size and proximity to outdoor spaces, a hospice-based sensory room, and an interactive art installation. Our findings may guide future recommendations for design considerations to enhance the psychosocial wellbeing of palliative care/hospice unit users.

Originality: To our knowledge, no scoping reviews have specifically examined design elements that have been implemented in palliative care or hospice units.

Relevance to conference theme: Recognizing the growing multi-disciplinary nature of palliative care research, our review is innovative in its exploration of design elements and interdisciplinary team members from environmental psychology, palliative care, and architecture. Given that our review only yielded three articles, there is a clear need for more research on the built environment in palliative care spaces.

How is equity of care measured by specialist palliative care services? Results of a scoping review

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Background: Despite health equity being a focus of specialist palliative care, the equity of care outcomes is not routinely measured by many services.
Objectives: This scoping review aimed to characterize measures used to assess equity in specialist palliative care delivery, to help programs identify measurement gaps and inequities for underserved populations.
Research approach: Databases were searched up to May 2023 [Medline (Ovid), Embase (Ovid), CINAHL (EBSCOhost), and Cochrane Central Register of Controlled Trials (Ovid)]. Equity factors were assessed based on "PROGRESS-Plus": Place of residence; Race/ethnicity/culture/language; Occupation; Gender/sex; Religion; Education; Socioeconomic status; and Social capital; Plus age, disability, and sexual orientation (and we added disease type (e.g., cancer or non-cancer). Following JBI scoping review methodology, abstract, full-text screening and data extraction were completed by two independent reviewers, with conflicts resolved by a third reviewer. Of 14,964 records screened for inclusion, 1451 full texts were reviewed, and 284 were included in the final analysis.
Relevance: Gender/sex, age, race/ethnicity/culture/language and disease type were the most common equity factors assessed. Sexual orientation, intellectual disability, being unhoused or incarcerated were rarely assessed. The three most common palliative care outcomes assessed for inequities were place of death, patient symptoms, and costs of care/resource use. Analysis of health administrative data was the most frequently reported measurement method for both palliative outcomes and equity factors.
Originality: Much is known about *inequity of access* to specialist palliative care but this work identifies important measurement gaps in how services are measuring *inequity of outcomes*.
Relevance to conference: This review informs the equity measures that are needed to improve palliative care delivery. Health administrative data is insufficient to explore many of the PROGRESS-Plus equity factors. Programs could adopt patient self-identified equity factors and methods that explore their experience outcomes (e.g., with targeted surveys and qualitative interviews) to understand the extent to which their specialist palliative care services are addressing systemic inequities.

Learning what matters: Care planning in the context of inequity

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Homelessness, poverty, racism, and a toxic drug supply result in early and unjust deaths among people living with social and health inequities in Vancouver's Downtown Eastside (DTES). Audits of patient records show that people living in this community are far less likely to be offered goals of care conversations even though social and health inequities contribute to a shorter life expectancy and higher risk of death than the general population. Furthermore, interagency documentation systems do not support transfer of information related to patients' health wishes. Yet, goals of care conversations are foundational to providing a palliative approach to care. A number of conversation frameworks are available to help clinicians initiate conversations about a person's values and priorities for care however, the language and structure of these existing guides do not generally lend themselves to conversations with people living with complex trauma, limited trust of healthcare personnel, substance use disorders and vast social inequities.
Our project aims to enhance opportunities for people living with health and social inequities and serious illness including use of unregulated drugs to express their wishes for care and have those wishes shared with care providers at critical points in their care journey. By the end of the project, we hope to be able to describe key factors and approaches that support these important conversations and to create education and practice resources based on these learnings. Working with community partners in health and housing, we will also establish guidance on how information about peoples' wishes for care can be shared between agencies when needed.
The learning phase of our 4-year project has involved conducting qualitative interviews with health and social care providers in the DTES as well as with people living in the community who access these services. The aim of the interviews is to learn about how and where conversations currently happen and with whom. Additionally, we have convened a table of representatives from various health, housing and spiritual care agencies in the DTES to discuss and validate the interview findings. We are partnering with

members of this community table during the knowledge translation phase to develop resources to support goals of care conversations and to generate and test ideas to improve information sharing between agencies and people.

We are not aware of any other research that has focused specifically on understanding and improving goals of care conversations that has included the voices of health, housing and spiritual care workers as well as residents of the DTES. The project team is committed to allowing the work to be shaped by the community. We look forward to continued learning and guidance from this community.

Funding for this project was provided by Healthcare Excellence Canada.

"Care is Connection": How place shapes experiences of care for precariously housed older adults nearing end-of-life

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Background: For older adults experiencing housing precarity, the absence of stable housing introduces unique challenges to accessing palliative care. While existing research highlights the importance of understanding how notions of home and social connection influence health and access to care, there is limited understanding of how these factors specifically impact precariously housed adults.

Objectives/purpose: This ethnographic study applies a combined geographic and health equity lens to explore the role of "place" in shaping the care experiences of older adults. We present three in-depth case reports of participants receiving support from a mobile palliative care team in British Columbia, Canada.

Research approach: Repeated participant observations were conducted over 12 months with precariously housed individuals (n=3) and their identified support persons (n=3), totaling approximately 65 hours of fieldwork. Additionally, interviews were conducted with service providers (n=7) directly involved in their care.

Relevance: Findings indicate that experiences of care were shaped by multiple factors, most notably being participant's access to their social connections, which were often determined by their living environment and directly related to their perceptions of home. This underscores the need to adapt current policies and advocate for more flexible care delivery models.

Originality: This original study presents new ways to conceptualize the home environment through the lived experiences of precariously housed individuals and highlights the need to recognize social connection as a form of care.

Relevance to the conference theme: This research aligns with the conference's focus on addressing social determinants of health within the field of palliative care by recognizing social connection as a key social determinant of health in advancing equity-oriented approaches to care.

Main source of funding: CIHR Project Grant PJT - 173369

Cut it out! Zine-making as method in equity-oriented public health palliative care research

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Background: Inner-city workers are at the forefront of responding to the ongoing toxic drug crisis impacting British Columbia, Canada. In addition to responding to repeated overdose events and deaths, the critical care inner-city workers are engaged in is compounded by inequities in death that impact people made structurally vulnerable by poverty, homelessness, and other structural disparities at the end of life. However, little is known about inner-city workers' experiences and perceptions of palliative care in this context. Furthermore, methods need to be developed to engage inner-city workers in equity-oriented public health palliative care research.

Objectives/purpose: We aim to explore how inner-city workers conduct and understand 'palliative approaches to care' by using zine-making as an art-based qualitative method. Zines are self-published maga(zines) that use a plethora of artistic means and are historically rooted in political and social movements. Zine-making is increasingly explored as a research method.

Research approach: A zine-making workshop was conducted with eleven inner-city workers from various organizations in British Columbia, Canada. The workshop was audio recorded, transcribed and thematically analyzed.

Relevance: Findings indicate that zine-making has a unique ability to derive new meanings and knowledge from the experiences of inner-city workers which can catalyze systemic, policy, and organizational changes to promote equity at end-of-life for people made structurally vulnerable.

Originality: This research proposes zine-making as a novel research method in the field of equity-oriented public health and palliative care research.

Relevance to conference theme: Through its focus on a novel research method, this research speaks to the conference's focus on innovative community participation approaches to work towards equity-oriented palliative care.

Identifying and understanding challenges and promising practices in the provision of hospice care for older people experiencing homelessness

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Background: Bed-based hospices are one-way older peoples experiencing homelessness (OPEH) access end-of-life care. Many OPEH experience unique palliative care needs due to substantial histories of trauma and structural violence, including complex mental health and substance use challenges. Most Canadian palliative care services are not designed to respond to these needs, and at times, actively deny care through exclusionary policies and practices. However, there are a small number of specialized hospices across Canada that have adopted policies and practices aiming to meet these unique needs of OPEH. While there is a small amount of emerging research in this area, the full scope and breadth of these inclusionary policies and practices is not currently known and understood.

Objectives/purpose: Conduct a comprehensive national environmental scan to identify and understand the challenges and promising practices from the perspective of hospice providers in the provision of bed-based hospice care for OPEH.

Research approach: In Winter 2025, Canadian hospices with stated mandates to provide care for OPEH or peoples experiencing other structural vulnerabilities will be recruited to participate in qualitative interviews, policy document reviews, and to provide quantitative organizational data. Interviews will be conducted with 3-4 staff at each hospice, each with different roles. Interviews will focus on their perspectives of the challenges in providing hospice care for OPEH and seek to identify the practices their hospice employs to address these challenges. Interviews will include exploring practices related to substance use, complex mental illness, Indigenous cultural inclusion, and gender. Thematic analysis will be used to identify common themes in the challenges faced. The diversity of practices addressing these challenges will be compiled and discussed. Interviews and analysis are currently underway with preliminary results expected by May 2025.

Relevance: Understanding the challenges facing OPEH in receiving culturally responsive hospice care, and the promising practices used to address these challenges at specialized hospices can help improve hospice care for this population both within and beyond these specialized hospices. These findings can be used by hospice and other palliative care providers to modify their policies and practices to better provide care for OPEH.

Funding: This research has been funded by a CIHR Health System Impact Fellowship.

Healing relationships between clinicians and visible minority patients in palliative care: Protocol for a qualitative study using interpretive description

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Context: Palliative care supports human dignity across the trajectory of a serious illness. In addition to addressing multiple dimensions of patient suffering, palliative care aims to foster healing-a relational process through which one experiences personal growth and transcendence. Palliative care clinicians build relationships with patients through communication practices that enhance trust and other relational elements. These relationships gain importance in the setting of serious illness as they hold the potential to mitigate patient suffering. However, people from visible minority groups face structural barriers and clinician biases that impede the formation of healing-oriented relationships and contribute to inequities in palliative care. We know little about their experiences of clinical relationships in this setting.

Objective: To explore the qualities of healing clinician-patient relationships from the perspective of patients from visible minority groups in palliative care.

Research approach: We will employ interpretive description as a qualitative methodology. We will invite patients (n=10-15) who identify as being part of a visible minority group and have had at least two outpatient palliative care visits. We will conduct 45-60-minute semi-structured, in-depth individual interviews and analyze these based on deductive-inductive thematic analysis. We will identify relational elements that patients value and that promote positive connections with clinicians. We will produce a rich description of "healing" from their perspective and understand the role of relationships in healing.

Relevance: By identifying clinician behaviors and other patient-informed factors that promote healing-oriented relationships, this research may inform clinical training programs that foster trust building and effective communication. These may in turn improve the quality of clinical relationships and palliative care services.

Originality: Researchers know little about how clinical relationships are experienced from the perspective of racially and ethnoculturally diverse patients. This research may contribute original knowledge to palliative care literature about "healing" from the perspective of those most vulnerable to experiencing multiple forms of systemic oppression during encounters with the healthcare system.

Relevance to conference theme: This research pertains to 'addressing social determinants of health in palliative care' and 'promoting culturally sensitive palliative practices'. By exploring how patients from visible minority backgrounds experience clinical relationships in palliative care, we will identify a range of behavioral, cultural, and social factors and practices that contribute to their sense of growth and transcendence of suffering. This research may inform the development of a clinical training program based on patient-perceived elements of healing relationships, which may have implications for delivering culturally safe palliative care and reducing inequities in care quality.

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Work-related grief and bereavement experiences of social and community workers supporting socially disadvantaged populations: A rapid scoping review

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Background/Context: Research on grief and bereavement among caregivers often assumes caregivers are housed, financially stable, and supported by strong social networks. In contexts of disadvantage (e.g., housing instability, poverty, racism), workers frequently fill essential care roles in challenging contexts. Little is known about their grief and bereavement experiences leaving critical gaps in research and support systems.

Objectives/Purpose: This study sought to collect and synthesize literature on the grief and bereavement experiences of social and community service workers supporting socially disadvantaged populations, highlighting gaps in the literature and identifying strategies for organizational and systemic support.

Research approach: A rapid scoping review was conducted using JBI methodology. Systematic searches of six databases (Medline, CINAHL, APA, PsycInfo, Web of Science Core Collection, Sociological Abstracts, and Social Work Abstracts), identified articles published until June 2023. Nine studies meeting eligibility criteria were included and qualitative approaches were employed to synthesize findings thematically.

Relevance: The review revealed three key themes: (1) Working in contexts of inequities, (2) Distress and its attributing factors, and (3) Support needs and strategies. The study highlights the lack of recognition and systemic support for non-medical workers as well as organizational and systemic strategies to reduce vulnerability to emotional distress, disenfranchised grief, and burnout.

Originality: This is one of the first studies to examine the grief and bereavement experiences of social and community service workers emphasizing their critical yet unrecognized role in the caregiving ecosystem. The limited number of studies identified suggests systemic inequities in research attention, policy development, and resource allocation for this workforce.

Relevance to the conference theme: This study underscores the important care that happens among people and communities outside palliative care services. Fostering diversity, equity, inclusion, and belonging in palliative care for people facing social disadvantage will require seeing, engaging and supporting this workforce in their essential care role.

Bridging the gap: Palliative care, Parkinsonism, and under-served populations

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Background/context of the study/work: Parkinson's disease (PD) is the second most common neurodegenerative illness affecting about 1.5 million Americans with unmet needs and impaired quality of life (QOL). Palliative care approaches have been successfully applied in other chronic progressive illnesses with minimal attempts to apply them to PD.

Objectives/purpose: To determine if a novel community-based, outpatient palliative care intervention improves QOL of patients of PD from under-served populations.

Research approach: This is a secondary data analysis of a large pragmatic, stepped-wedge comparative effectiveness trial. To test the effect of treatment (post vs pre) over time (12- and 6-months vs baseline) between non under-served vs under-served groups, we created a variable called "under-served demographic" with the following: rural (defined as a census RUCA1 code in the range [7,10]), annual household income $< \$50$k, not of White or Caucasian race, or of Hispanic ethnicity. We measured QOL using Quality of Life in Alzheimer Disease Scale (QOL-AD). We ran t-tests to look at group differences at baseline and mixed-model regression analyses to examine longitudinal differences between groups. All statistical analyses were performed using SAS version 9.4 (SAS Institute). We demonstrated statistically significant treatment overall effect for non-under-served groups with improved QOL at 6 (marginal, $p = 0.06$) and 12 months ($p=0.04$), but not for under-served groups ($p=0.36$ and 0.29, at 6 and 12 months, respectively). However, we achieved statistically significant interaction effect for both non-under-served (post vs pre vs 12-month vs baseline, under-served demo = no; estimate, 2.89, 95% C.I., 0.49 to 5.30, $p = 0.05$) and under-served (post vs pre vs 12-month vs baseline, under-served demo = yes; estimate, 2.39, 95% C.I., 0.33 to 4.46, $p = 0.05$) groups. Considering our objectives, the interaction effect suggests that for the under-served demographic, there is a statistically significant positive change in QOL-AD when comparing the intervention to standard care and 12-month assessments to the baseline. Specifically, the estimate of 2.39 indicates a meaningful increase in the QOL-AD, with a 95% confidence interval ranging from 0.33 to 4.46, confirming that this effect is unlikely to be due to random chance ($p = 0.05$).

Relevance: Findings suggest that the intervention is effective in improving QOL for underserved populations over time and warrants future research to further explore the effect of palliative care interventions tailored to under-served populations.

Originality: Patients of PD from under-served groups are often invisible, have unique needs, and require innovative and non-traditional models of care.

Relevance to conference theme: Our work prioritizes underserved communities to ensure they receive compassionate and comprehensive care they deserve and need.

Identifying Equity Gaps in Palliative Care Access: A Co-Design Process

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Background: As palliative care (PC) access increases over time, inequities continue, in use and timing of access across different factors.

Study Objectives: The overall study objective was to explore, using administrative data, differences in specialist PC (SPC) access and use, when looking at various equity factors, as directed by our co-design stakeholders.

Research approach: We used a co-design process whereby patients, providers, researchers (including equity researcher), health system leaders and policy makers informed the research questions, methods, data sources and analysis plans. All decedents who died from any chronic disease from 2013-2021 in Alberta were included in the sample. They were linked to health resource use in their last year of life, using administrative data. In this first phase, three equity factors were prioritized as exposures of interest: diagnoses (cancer vs non-cancer), rural-urban residence and socioeconomic factors (composite quintile index from least deprived to most deprived). Outcomes of interest were defined as use of SPC at any point before death (proportion) and timing of first use of SPC (median).

Relevance: During successive meetings, our co-design stakeholders identified 8 equity factors to explore: Income level, Socioeconomic marginalization index (Pampalon Index), Age, Sex, Housing status, Diagnosis, Rural-urban residence and Immigrant status. Across 166,301 decedents, SPC use was 37.1%, with 1st SPC use occurring a median of 33 days before death. SPC use was higher in cancer (70.2%) vs non-cancer (21.7%), occurring a median of 38 days vs 23 days before death respectively. Urban residents had more SPC use (45.1%) vs rural residents (17.0%) without difference in timing (32 days vs 34 days). The most deprived residents had lower SPC use (38.8%) vs least deprived (44.8%), but no difference in timing (32-33 days). However, the difference in SPC access between the most deprived vs least deprived were attenuated in the urban cancer cohort (83.4% vs 85.1%) and rural non-cancer cohort (8.1% vs 9.2%).

Conclusion: In a large publicly funded health system, there continues to be inequities in PC access in populations who live in rural areas, have non-cancer diagnoses and are most socioeconomically deprived. However, these differences are attenuated when looking at combinations of equity factors. Leaders and policy makers should carefully tailor interventions based on the intersections of diverse equity factors.

Originality: A co-design process ensured stakeholders were involved in research question development from the beginning, to make data collection and analysis relevant and acceptable for patients, clinicians, health system leaders and policy makers.

Relevance to conference theme: Equity and diversity factors identified within a co-design process should lead to more direct impact on health systems and policies, thereby promoting more compassionate and comprehensive care for all.