

SYMPOSIUM ON INTEGRATING A PALLIATIVE APPROACH FOR STRUCTURALLY VULNERABLE PEOPLE IN VICTORIA

OCTOBER 17, 2017, 0900-1600
VICTORIA CITY HALL
ANTECHAMBERS

MEETING
REPORT

DR. KELLI
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MOLLISON



University
of Victoria
Institute on Aging
& Lifelong Health



i PANEL
INITIATIVE FOR A
PALLIATIVE APPROACH IN NURSING:
EVIDENCE & LEADERSHIP



University
of Victoria
Nursing



CIHR IRSC

EQUITABLE ACCESS TO CARE STUDY TEAM

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Background

The UVic *Equitable Access to Care* study team is finalizing a 3-year ethnographic, CIHR-funded, research project documenting the end-of-life experiences of people facing poverty, homelessness and inadequate housing, racialization, stigmatization of mental health and substance use, and other structural inequities in Victoria. On October 17, 2017, we held a symposium to share study findings and recommendations, offer panel presentations on research and promising practices, and engage key stakeholders in strategy discussions to move the agenda forward on improving access to and quality care at end-of-life for structurally vulnerable people in Victoria.

Presentations included:

- Access to end-of-life care for structurally vulnerable people: research findings
- From evidence to practice: promising practices in delivering palliative care to structurally vulnerable people
- From analysis to action: lessons learned from research on integration of a palliative approach to care

Panels included:

- Considerations for the integration of a palliative approach in our local health systems
- Supporting providers in inner city health, housing & support services to integrate palliative approaches to care
- Supporting structurally vulnerable people and their chosen supports to engage in service planning

In attendance were representatives from the following organizations: AIDS Vancouver Island, Circle of Sage, the City of Victoria, Victoria Cool Aid Society, Greater Victoria Coalition to End Homelessness, Inner City Health Associates (Palliative Education and Care for the Homeless, Toronto), Island Health (Aboriginal Health, Home and Community Care, Palliative and End of Life Care, and Victoria General Hospital) Journey Home Project, Ministry of Health (Palliative and Dementia Care), New West Hospice Society, Our Place Society, Pacifica Housing, University of Victoria (Institute on Aging & Lifelong Health, School of Nursing, Centre for Addictions Research of BC, School of Social Work), and Victoria Hospice Society.

Palliative Outreach Resource Team

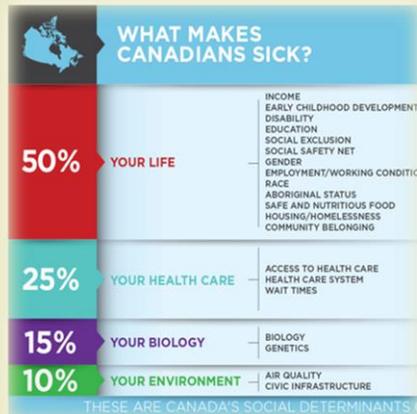
This research and event are the result of deep collaboration between researchers and representatives from community agencies who are part of the Palliative Outreach Resource Team (PORT). PORT is comprised of healthcare providers and community partners including Cool Aid Community Health Centre, AIDS Vancouver Island, Dandelion Society, Our Place Society, Victoria Hospice Society, and the University of Victoria (UVic) Institute on Aging & Lifelong Health and the UVic School of Nursing who are networking to improve access to quality palliative care for people who are nearing end-of-life and who live on the street or are housed unstably.

Key Themes

The following are key themes that emerged from our presentations, panels, and discussions:

Social determinants of health in life and death

At this symposium, presenters and participants recognized the importance of the social determinants of health (SDOH) in life and in dying. There is a need for structural and systemic change that improves people's access to quality care upstream, rather than only when a person is at the end-of-life (EOL). People's capacity to be resourceful changes at the EOL, and as a person declines, they have less access to food, income, health services and social supports such as friends, and family. When a person is approaching EOL, SDOH concerns remain an essential part of good palliative care. For instance, people need safe, appropriate housing where they can die in place if they wish,



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where health and social services can come around them in a coordinated way; they need access to food to sustain well-being and transportation to enable them to get to medical appointments and have pain and symptom needs met.

Strengthening partnerships, knowledge sharing, and communication to integrate systems

Another key theme emerging from this symposium is the need for improved communication and coordination between health care (e.g., acute care, palliative care, home & community care) and the inner city services (e.g., housing, shelters, and health services) to achieve integration and improve access to quality care at EOL. Presenters and participants expressed a desire for dedicated time and space to learn from one another, share knowledge from diverse disciplines, communicate about issues, feel 'heard,' and strategize on moving the agenda forward. Research with engaged partners was highlighted for its importance in highlighting this issue and bringing people together who are passionate about making change. Our discussions acknowledged the importance of a "palliative approach" for this population, assembling a consortium of service providers, and raised questions about how we can involve structurally vulnerable people and their chosen family and friends in developing a service and where the funding would be held and administered.

Participants said the following people should be "at the table":

- Provincial Ministries (Health, Primary care, Mental Health & Addictions)
- Indigenous organizations and communities
- Inner city health, housing, and social services
- Island health – Home & Community Care, and home support
- Service users (people with lived experience of homelessness) and street/ chosen family
- Volunteer and civil society groups
- Acute care/ hospitals
- Palliative care community
- Municipal government

Adapting a palliative approach for structurally vulnerable populations

A key theme of the day was how we use the concept of a palliative approach in settings where structurally vulnerable people live and die. A palliative approach is different than specialized palliative care. It takes principles of palliative care and adopts them early in the course of a person's life-limiting condition, adapts strategies to meet the person's needs and those of their chosen supporters, and embeds practices into usual care in settings not specialized in palliative care.* While palliative care is already largely happening where people live, we need to build capacity among organizations serving this population including developing policy, education and tools, and access to support to re-frame the work that is already happening as a palliative approach to care. Integrating a palliative approach requires executive leadership to make it an organizational priority and leaders within each organization to support and facilitate education, teaching and support for front line staff to support their clients at EOL. There was also an expressed need for a culturally appropriate space for people to go when they need 24/7 support/health care but don't need to be in acute care.

SHIFT YOUR THINKING...

TO A PALLIATIVE APPROACH

A palliative approach is different than specialized palliative care. It takes principles of palliative care and:



ADOPTS principles EARLY
In the course of a person's
life-limiting condition



ADAPTS strategies to meet
patient and family needs



EMBEDS practices into
usual care in settings not
specialized in palliative
care

The conversations on a palliative approach throughout the day brought forward many questions, including:

- How do service providers, often not medically trained or without access to medical records, identify a person on a palliative trajectory? (e.g., How do we teach people to notice signs of decline? How do we educate about services available?);
- How do we communicate with the person and their chosen family about their care plan, their goals of care, their worries, hopes, and fears? How can the plan of care reflect this and cross settings?
- How do we adapt palliative knowledge and skill for this population? What knowledge and skill of caring for structurally vulnerable people needs to inform palliative dimensions of care? What practice tools do we need to support working with this population at EOL?

*Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Stajduhar, K. (2016). Conceptual foundations of a palliative approach: A knowledge synthesis. *BMC Palliative Care*, 15, 1-14. <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-016-0076-9>



Developing culturally safe, palliative approaches to care

Throughout the day, we discussed the importance of engaging chosen family and caregivers including street family and front line workers in the development of a service delivery model for a palliative approach to care. This includes asking people how they would design a palliative approach for themselves, friends, and family members. As one panel member indicated, last year alone there were 17 Indigenous homeless people who died on the streets of Victoria. Moving forward on developing a palliative approach for structurally vulnerable people must include the specific experiences and needs of urban Indigenous people who face both dispossession and displacement from their lands, culture, and biological families. Indigenous homeless people who are facing chronic conditions do not access care because of discrimination and racism in the health care system. This makes it especially difficult to identify people who are in need of a palliative approach to care. It is essential that we make all health care more culturally safe so that homeless people are supported further upstream to access quality care that is dignified and respectful.

Education, mentorship, and support

It was well recognized by presenters and participants that there is a need for education and tools to adapt a palliative approach for structurally vulnerable people. On one hand, there is a need for education for general health care, and home & community care, and home support, on the reality of homelessness and palliative care, and approaches that are trauma and violence informed, harm reduction based, and culturally safe. On the other hand, there is a need for education, resources, and tools for inner city workers about integrating a palliative approach including knowledge about illness trajectories, adapted prognostic indicators of decline, having end-of-life conversations, and the palliative supports and resources available to their clients. Many inner city organizations spoke to the need for a handbook where they could access resources about palliative care services including numbers to call for support. It was also acknowledged that there needs to be more education for physicians on prescribing to people with active substance use. However, it was recognized that education and tools alone will not create culture shift; engagement, and ongoing mentorship and coaching of staff, and opportunities for dialogue and practice, are needed.

Challenging stigma and navigating risk management policies

Perceived risk in inner city housing and shelter facilities is a key barrier to people receiving health services and ability for people to die in place. Participants discussed the need to reduce stigma about structurally vulnerable people in settings where they live and to facilitate access through partnerships and creative solutions. For instance, since trust is a key to providing care in this population, could a housing or support worker partner with a home and community care nurse to do a home visit with an individual in a shelter setting? Could we provide mentorship opportunities for health care workers who do not have experience working in the inner city?

As much as we try to bust myths and address perceived risk, we cannot always control the environments in which we work. We also need to address instances where real risk is a reality. It was acknowledged that people working in inner city health, housing, and shelters have developed strategies for minimizing risk and promoting safe working environments. What can we learn from these strategies and experiences? How can the policies and practices that exist instil confidence in regulatory bodies that seek to minimize risk (e.g., Worksafe)?



Support for workers and chosen family members

Throughout the day there was powerful acknowledgement of the importance of front line workers and street family as often informal, unrecognized, and unsupported caregivers at EOL. There was an agreement that we need an explicit recognition of an inner city population that is deeply bereaved, facing huge numbers of deaths as a result of the overdose emergency that continues to occur, unabated. The classic divide between ‘workers’ and ‘clients’ is no longer the case as there are workers coping with deep bereavement, often in housing crisis and living in poverty themselves, who are caring for a population facing the same barriers. Managers in inner city housing, health, and social services are constantly balancing the need to provide respectful, compassionate support to tenants and clients, but also to staff. If we are moving forward to develop a palliative approach in this community, it cannot informally fall on the people who are already facing significant strain in their jobs. Supporting service providers to develop and implement a palliative approach includes building on existing skills and on-going in-services, paid time for education, use of volunteers to fill in gaps in care including cleaning, meals, visits etc., a commitment to grief counselling and other strategies to address burnout, and creating a culture that supports staff. It was recognized that workers need to experience, firsthand, their client getting access to good quality EOL care; one table came up with the idea of the “one good death” project showing how it can work when services are coordinated at EOL.

WHAT WOULD A MODEL OF PALLIATIVE CARE FOR STRUCTURALLY VULNERABLE PEOPLE LOOK LIKE IN VICTORIA?

During the day, we began talking about the service model that would work in our community. Some elements of this model that were discussed included:

- Building capacity for a palliative approach in the community; this is not the responsibility of one organization, it's all of our responsibility. We could develop a consortium of organizations that are invested in this issue or it could be taken on by an existing collaboration.
- Harm reduction, palliative care, cultural safety, violence and trauma informed, are core guiding principles for the service model
- Nurse care coordinator model to provide continuity of care between inner city health, housing, and service organizations, and palliative care, as the person transitions through settings.
- Mobile, team model with expertise from different disciplines and professions
- Physician support from physicians who have a palliative orientation and expertise who can provide mentorship and support to primary care physicians for medical care with an emphasis on SDOH and whole person care
- Palliative beds specific for people experiencing structural vulnerabilities and those who need to transition between hospital and home
- Peers who can work with a nurse care coordinator to plan and participate in care for their community; working closely with nurse care coordinator
- The Palliative Outreach Resource Team (PORT) takes lead building capacity and providing education in our community including creating handbook for housing providers
- Volunteers from existing organizations who are trained to work in the inner city; can support existing gaps including cleaning, meals, grocery shopping, visits, etc.
- Home care nursing and home support team that feels comfortable to work with structurally vulnerable population and in diverse settings to provide continuity of care
- Flexible admission and eligibility criteria; referrals to service not exclusive to physicians; can come from individuals and inner city agencies

Next steps:

1. Take research and symposium findings back to PORT and continue developing model of palliative care for people experiencing structural vulnerabilities
2. Meet with leaders from organizations who have expressed interest in moving this agenda forward
3. Compile list of contacts of people in organizations and a broader community who have expressed interest in keeping updated on progress. A newsletter will be sent out with project updates every 2 months.

ACKNOWLEDGEMENTS

A huge thank you to the Canadian Institutes of Health Research (CIHR) for funding this symposium; the City of Victoria for providing the venue; James Taylor for the Territorial Acknowledgement; the Palliative Outreach Resource Team (PORT) and Victoria Hospice for ongoing collaboration; our CIHR Planning & Dissemination grant research team (Kelli Stajduhar, Sheryl Reimer-Kirkham, Kristen Kvakic, Grey Showler, Bruce Wallace, Bernie Pauly, Naheed Dosani, & Douglas McGregor); and all of our volunteers, presenters, panelists, and participants!

THANK YOU

For more information about this report or the Equitable Access to Care Study, please email Ashley Mollison at equitableaccess@uvic.ca

or follow us on Twitter @access2care

Symposium on Integrating a Palliative Approach for Structurally Vulnerable People in Victoria

October 17, 2017 · 0900 – 1600 · Victoria City Hall Antechambers

Time	Title	Presenter(s)
0900 – 0930	Territorial Acknowledgement & opening remarks	<p>James Taylor <i>Anishnaabe Ojibwe, Curvelake First Nation</i></p> <p>Olivia Stajduhar <i>Grade 7 Student, Arbutus Global Middle School</i></p>
0930 – 1000	Access to end-of-life care for structurally vulnerable people: Research findings	<p>Dr. Kelli Stajduhar <i>Professor, UVic School of Nursing & Institute on Aging & Lifelong Health</i></p>
1000 – 1030	From evidence to practice: Promising practices in delivering palliative care to structurally vulnerable people	<p>Dr. Naheed Dosani <i>Project Lead and Founder Palliative Education And Care for the Homeless (PEACH), Inner City Health Associates, Toronto, ON</i></p> <p>Ashley Mollison <i>Project Coordinator, Equitable Access to Care Study UVic Institute on Aging & Lifelong Health</i></p>
1030 – 1045	<i>Coffee break</i>	
1045 – 1145	Panel: Considerations for the integration of a palliative approach in our local health systems	<p>Kathy Stinson <i>Executive Director, Victoria Cool Aid Society</i></p> <p>Lois Cosgrave <i>Director, Palliative & End-of-Life Care, Island Health</i></p> <p>Dr. Douglas McGregor <i>Medical Director, Victoria Hospice Society</i></p> <p>Le-Ann Dolan <i>Director of Operations, Our Place Society</i></p>
1145 – 1215	From analysis to action: Lessons learned from research on integration of a palliative approach to care	<p>Della Roberts <i>Clinical Nurse Specialist Palliative & End-of-Life Care, Island Health</i></p>
1215 – 1300	<i>Lunch</i>	

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Time	Title	Presenter(s)
1300 – 1400	Panel: Supporting providers in inner city health, housing & support services to integrate palliative approaches to care	<p>Kristen Kvacic <i>Director of Programs, AIDS Vancouver Island</i></p> <p>Tyler Schaus <i>Manager of Supported Housing or</i> Angela McNulty-Buell <i>Assistant Director of Support Services</i> <i>Pacifica Housing</i></p> <p>Grey Showler <i>Director of Health & Support Services</i> <i>Victoria Cool Aid Society</i></p> <p>James Slack <i>Team Lead, Cottage Grove, Victoria Cool Aid Society</i></p>
1400 – 1445	Panel: Supporting structurally vulnerable people and their chosen supports to engage in service planning	<p>Bernice Kamano <i>Community Advocate</i></p> <p>Penny Cooper <i>South Island Manager, Aboriginal Health</i> <i>Island Health</i></p> <p>Dr. Bernadette Pauly <i>Scientist, UVic Centre for Addictions Research of BC</i></p>
<i>Coffee & snacks available, no break</i>		
1445 – 1545	Strategic visioning exercise: Moving an agenda forward on integrating a palliative approach for structurally vulnerable people in Victoria	<p>Dr. Kelli Stajduhar <i>Professor, UVic School of Nursing & Institute on Aging & Lifelong Health</i></p>
1545 – 1600	Closing remarks	<p>Marianne Alto <i>Victoria City Councillor</i></p>



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