A PORT IN THE STORM
A DAY OF EDUCATION AND DISCUSSION ABOUT EQUITABLE ACCESS IN PALLIATIVE CARE FOR STRUCTURALLY VULNERABLE PEOPLE IN VICTORIA

DECEMBER, 2015
On Thursday, October 29, the University of Victoria Equitable Access to Care Study Team (PI Kelli Stajduhar), Victoria Hospice, and the Palliative Outreach Resource Team (PORT) hosted an interactive and educational event about palliative care for structurally vulnerable people. Structural vulnerability recognizes that particular groups of people are more vulnerable to harm as a result of intersecting factors (e.g., poverty, homelessness, gender, disability, race, illicit drug use, mental health issues, etc.).

The objective of this event was to foster dialogue between formal palliative care providers (e.g., hospice personnel, home care workers, etc.) and downtown service providers (i.e., health, housing, faith and social service organizations) to identify challenges in our community with regards to palliative care access for these populations.

The day began with a welcome from City Councillor Marianne Alto who spoke about the significance of dignified palliative care services for Victoria’s inner city population. Participants then heard about current research on palliative care and structurally vulnerable populations through presentations by Dr. Kelli Stajduhar, Lead Investigator with the University of Victoria’s Equitable Access to Care study, and Ryan McNeil from the BC Centre for Excellence in HIV/AIDS, a leading researcher in the field.

A series of presentations followed on promising practices in palliative care from Dr. Naheed Dosani, lead physician with PEACH (Palliative Education and Care for the Homeless) in Toronto; Dr. Sue Burgess, a physician providing palliative care in Vancouver’s Downtown Eastside; and Victoria’s Palliative Outreach Resource Team, represented by Grey Showler. After lunch, a panel of practitioners from Angela McNulty-Buell (Pacifica Housing), Dr. Danica Gleave (Cool Aid Community Health), Dr. Deb Braithwaite (Victoria Hospice), Rev. Allen Tysick (Dandelion Society), Darren Schweitz (Our Place Society), and Kristen Kvakic (AIDS Vancouver Island) spoke about the challenges to providing and accessing palliative care for the people they serve.

The remainder of the event was spent in small group discussions where participants with diverse employment backgrounds, including front line workers, health care professionals, managers, executive directors, spiritual practitioners and people with lived experience of poverty and homelessness participated in discussions about challenges to palliative care access in Victoria. Finally, Dr. Dosani facilitated break-out groups where participants had the opportunity to discuss how 7 palliative care principles (i.e., flexible admission
criteria; consistent and continuous case management; maximize flexibility of program policies; foster peer-support networks; employ diverse and holistic care models; prioritize client dignity; provide palliative care within intensive supportive housing) could be implemented in various organizations for a community-based response to this important issue.

Evaluations from the day suggest that the day was a great success and people left feeling inspired. The Equitable Access to Care study will continue with data collection until spring 2016. We plan to host another community forum with people who have lived experience of poverty and/or homelessness to seek feedback on findings and project recommendations.

Thanks to our generous funders and contributors: The Sovereign Order of St. John of Jerusalem Knights Hospitaller Victoria Commandery, Victoria Hospice, the Palliative Outreach Resource Team (PORT); the Canadian Institutes of Health Research (CIHR) and the UVic Centre on Aging; and our presenters, panelists and facilitators, and Terry Ducette for the cover photo.

The following are key themes that emerged from small group discussions at “A PORT in the Storm.” At two points during the day, the participants were divided into small groups. The first small group session was focused around the question: “In your opinion/experience, what are the major challenges in our community in terms of providing palliative care to structurally vulnerable people?” and the second around the 7 principles of palliative care facilitated by Dr. Naheed Dosani. Notes were recorded on large sheets of paper by an appointed or elected group facilitator and compiled into themes by the EAC project coordinator.

The purpose of this document is to compile what we heard from people in our community about palliative care for structurally vulnerable populations including recommendations for improving access to palliative care. This document represents a starting point for this discussion in our community and it is our hope that this conversation continues to happen. Please see resources at the end of the document for more information.
KEY THEMES AND RECOMMENDATIONS FROM “A PORT IN THE STORM”

Theme 1: The need for palliative education & awareness of the ‘changing face of palliative care’

- For the public, decision makers and program designers:
  - Homelessness cuts a person’s life expectancy by 50%
  - Need to change the face of palliative care for public and providers: recognize that a palliative approach is relevant for those living with chronic, life-limiting conditions, not just older adults who are dying
  - Need to change the definition of ‘home’ and recognize that for structurally vulnerable people, shelters, transitional housing and supportive housing may be ‘home’
  - Senior levels of government need education as to what is needed on the ground
  - Use of terminology to refer to structurally vulnerable populations can reduce dignity (e.g., marginalized; ‘hard-to-reach’)

- For community front line workers and outreach teams who are not specialized in palliative care:
  - Need more education on palliative care including how to identify those who could benefit from a palliative approach
  - Increased support around acknowledging death and knowing how to have a conversation about death and dying
  - Could there be a referral model for support/networking around death and dying issues?
  - PORT is an excellent resource for information/resources about palliative care for structurally vulnerable people

- For health care providers not familiar with working with structurally vulnerable populations who are in need of education around a palliative approach to care:
  - There are embedded assumptions around care provision (e.g., access to a home, family support, financial resources) that make care for this population much more challenging.
  - Need education on homelessness and poverty
  - Need for education on how to administer pharmaceuticals for pain management for people who use drugs
  - Health care providers working in palliative care, in home care and in home support may be nervous dealing with this population because they do not have the training
  - Education and networking with community outreach teams -- what does each team do? Could they provide palliative care and supports?
  - Need a different approach to building trust with different populations; skills in trust-building may not transfer to other populations; not everyone needs/wants to be treated the same way
  - The provision of palliative care within institutional settings, like palliative care units, does not always work for this population of structurally vulnerable people. Issues identified included:
    - Lack of privacy
    - Restrictive policies that do not address the unique needs of the population
    - Judgements from staff because of the person’s lifestyle
Recommendation: The need for diverse, holistic care models

- Support more multidisciplinary teams
- Champion systems that are inclusive and remove those that are exclusive
- Challenge structural, policy, professional barriers
- Involve community in service planning
- Integrate new interventions into existing models
- Use diverse models of care (e.g., nursing specialty for structurally vulnerable populations)
- Site for supervised consumption and palliative care
- Relational care: smoother, singularly resourced, transitionally focused, integrated system that takes people through early recognition of palliative needs all the way to death

Theme 2: The need to combat stigma, fear and judgement in our health services

- Prevalent stigma and judgement that people ‘choose’ to be homeless; homeless people are dehumanized
- Structurally vulnerable people who are dying face a ‘double stigma’ around homelessness, multiple illnesses, substance use, etc.
- The problem of people being profiled as homeless when they walk through the door and need for change in attitude in health care clinics and settings; lack of ‘cultural safety’ for this population
- People are alienated and socially isolated; the focus needs to be on trust and relationship building
- Service providers need to be accepting of difference and we need to shift the way we think about the care we provide for this population
- Structurally vulnerable people and many front line workers do not trust that the system will provide adequate and humanized care in the face of dire need
- Language used to talk about structurally vulnerable people can sometimes perpetuate stigma
Recommendation: The need for health care providers to be self-reflective in their practice

- Education and self-reflection on own behaviours and beliefs can help health care providers to build skills
- Shift framing from individual risk factors to structures that create risk (e.g., being Indigenous is not a risk factor; being part of a colonial system creates risk)
- Health care providers need to understand the cultures of the people they serve in order to plan appropriate and acceptable services
- Change our language to reflect the change in our care focus to structural conditions
- Recognize that we are flawed people too and that our flaws help us to be genuine
- The importance of transferring power to reduce differences in power and promote dignity; acknowledge that race is power differential

Recommendation: Fostering peer support networks for education and systems navigation

- Invaluable to have experiential voices as part of care design and delivery; excellent for relationship building and education
- Start with a dedicated team
- Importance of developing opportunity/space for appropriate mentorship
- Monetary incentives – peer positions need to be paid positions
- Serving life: informal – buddy system and care provider; formal – create training and education program within team
- Needs to be an integrated community initiative
- Look to peer groups and programs in the community (e.g., Umbrella; Hospice 101; Use “Street School” from AVI & SOLID as models for training)

Theme 3: Navigating the system & challenges accessing palliative care resources

- Budget cuts and continual reorganization of health services has resulted in discontinuity of care; this creates a situation where there is little ability to focus on trust and relationship building, an essential component of caring for structurally vulnerable people
- Community groups and agencies are not working together; competition for funding pits agencies against each other (not just community organizations but policing, the City; health authority, etc.)
- Policies prohibiting health care providers from serving structurally vulnerable people (e.g., not allowing health care providers to enter certain housing complexes) place them in positions of having to “break the rules” of their organization in order to provide access to services that are desperately required by people
- Navigating the health care system for structurally vulnerable people and service providers is a major challenge
  - History of violence follows people (e.g., 'purple dotted')
- Rules and guidelines are restrictive to people getting service where they live (e.g., shelters/ some supportive housing units); currently there is little flexibility and liability is a concern
  - Home care policies deny access to certain buildings because of safety concerns
- Lack of specialized palliative care resources for structurally vulnerable populations
  - The potential for specialized resources have the potential to re-stigmatize
- There is a lack of palliative care resources, in general
  - Lack of respite beds is a major challenge; waiting list for respite beds
  - Access to palliative care beds that require a per diem to be paid create a barrier to access for people who cannot afford it
  - Lack of transitional care beds
  - Lack of specialized hospice bed/services within shelters
- The requirement of a family doctor for accessing palliative care or chronic disease management:
  - Lack of GPs -- Over 10,000 orphaned patients in Victoria
  - Challenging to access walk-in clinics (e.g., one file, not one doc; challenge getting to walk-in clinics)
  - Access to medications to support quality end of life care is problematic

**Recommendation: Consistent & continuous case management for systems navigation**
- Walk beside as a ‘tour guide’ rather than telling people what to do
- Meet out in the community rather than expecting client to come into office; could take a long time to come into an office
- Safe, shared space; build trust by being there in person
- Consistency in staff; this need is especially important for this population
- Trust and safety needs to be built through little gestures that recognize the person’s humanity
- Services need to transform
- Health care providers can use principles of taking the time, showing up/accountability, human connections, good for health care provider wellness and care for client
- Health care providers who have built trust can vouch for other providers on the team and say that the resources are trustworthy
- “Nothing about us without us”; interdisciplinary teams should include peer support workers

**Recommendation: Flexible eligibility & admission criteria**
- Clarify and educate about the criteria for palliative care services
- Services need to be flexible to recognize people’s agency
- Harm reduction needs to be integrated
Theme 4: Lack of housing and place for structurally vulnerable people in Victoria

- Lack of physical space for structurally vulnerable people in Victoria
- The requirement of a ‘home’ to receive palliative care
- The lack of affordable and appropriate housing in Victoria
  - Can’t have ‘home deaths’ without a home
  - Housing should be tied to income (i.e., social housing)
  - Case management to support long term
  - Death at home can work with support and education
  - People’s medical needs become too high for supported or transitional housing and there is nowhere to go but acute care
  - Providing good treatment management when one of the presenting issues is a housing issue
- “Hot potato”: Needing to evict someone so they get medical care
- Lack of palliative beds in shelters or supported housing facilities

Short term recommendations:
- Recognize that palliative care happens in community as well as in Hospice and through formal palliative care services; change the definition of ‘home’
- Some supported housing facilities are prepared to keep residents there at end-of-life with support from medical professionals
- Housing criteria – include palliative as criteria to scoring/need for housing
- Found some people in shelter were comfortable; allows home address, stability

Long term housing recommendations:
- Link to the City’s “Housing First” Municipal Housing Strategy for housing
- Need quickly accessible, “nimble” housing response for palliative care
- Provide Palliative Care within Intensive Supported Housing
  - Harm reduction based
  - Multidisciplinary care team (‘map readers’; peer workers!)
  - Multiple levels of care within one building – fluidity, flexibility, continuity of care, maintain community
Theme 5: Risk management and the impact on access to care
- Banning/limits for home care re: buildings in community because of safety concerns
  - When someone becomes palliative, their home becomes a workplace and ‘work safe’ applies
  - Combination of smoking and oxygen an issue
  - Medical cannabis smoking also an issue
  - Challenge of balancing work safety and needing to provide services; May not be real fears
  - Risk management policies mean that services are not provided
  - There is a list that limits home care visits to certain buildings: is list up to date?
  - Rules about entering places with cockroaches has been an issue at times
- Defining the caregiver: Home care nurses need to be able to trust a primary caregiver with meds – need palliative outreach workers
- Need right home care worker at right time
  - Outreach nurses can do some of the same things as home care
  - Communication and avoid duplication
  - Need more collaboration

Recommendation: Maximizing flexibility of program policies

- **Service providers and people who use the services should be involved in developing the policies**
- **Flexibility in work safe issues and liability**
  - Smoking is a barrier to care; need flexibility in non-smoking policies:
    - Solutions (like ventilation systems) may already exist in other places that could be replicated
    - Having home care meetings in other locations like Tim Hortons, where possible
    - Currently not many official policies around illegal drug use and alcohol
- **Spaces designed for a variety of people – how can we adapt rules so that everyone can get care? Designing rooms to be cleaned easily?**
- **Joint visits between home care staff and housing/outreach staff**
- **Supporting street family and other residents in the building to be primary care givers**

Theme 6: Challenges identifying and providing palliative care to structurally vulnerable clients
- Challenges identifying who the palliative clients are and getting the care early:
  - Challenges in deciding who and when to receive care – “all of our clients are palliative”
  - Also need skills to know whether a person is dying/palliative with all potential health complications. For example, a small additional illness could tip them over the edge
  - Challenges getting palliative designation through Home & Community Care
  - Who would benefit from a palliative approach?
- Challenges providing palliative care:
Recommendations:

- **Education on symptom management with people who use drugs:**
  - Need more mental health education in primary health care and address the destabilization (mentally and physically) from illicit drug use
  - Need to look at responses and ways of helping individuals manage illicit drug use

- **Prioritize Client Dignity:**
  - Dignity is a core issue but taken for granted
  - Dignity means different things to different people
  - Respect client choice
  - ‘Checking’ assumptions about structurally vulnerable people – e.g., income; number of hospitalizations/emerge contacts; what is a ’good death’? Who is change being made for?
  - Being caring and listening; giving time
  - Importance of consistent providers
  - Focus on wellness (not just physical)
  - Need to address childhood trauma
NEXT STEPS

The *Equitable Access to Care study* will be completing data collection by the fall of 2016 and there will be future opportunities to engage in this topic and recommendations emerging from the study. Next year, we will also host an event for people with lived experience of poverty and homelessness to provide feedback on study recommendations. In the meantime, feel free to take a few minutes and explore the *iPanel website* (http://ipanel.ca), a collaborative with the common goal of advancing the further integration of a palliative approach into the healthcare system.

If you are interested in conducting an interview with us about your experiences providing or accessing palliative care for structurally vulnerable people or if you have any comments or suggestions for the research work going forward, please don’t hesitate to be in touch at equitableaccess@uvic.ca.

For more information about PORT, palliative care for people who are structurally vulnerable, or to book a workshop please see the PORT description on the next page.
THE PALLIATIVE OUTREACH RESOURCE TEAM (PORT) IN VICTORIA

Information for Health Care and Housing Staff

Healthcare providers and community partners in Victoria, BC are networking to improve access to and the quality of hospice palliative care for people who are dying and who live on the street or are housed unstably. **PORT members** represent different professions and disciplines from:

- Cool-Aid Community Health Centre
- AIDS Vancouver Island
- Dandelion Society
- Our Place
- Victoria Hospice
- University of Victoria School of Nursing

Serving people who live on the street or who are housed unstably means honouring the unique experiences, hopes, strengths, and preferences of each individual and their family. **Providing care may mean** working with:

- Fragmented and irregular health care
- Legacies of prejudice, colonialism, violence
- Complexities of living with mental health issues
- Complexities of living with substance use issues
- Difficulties contacting family

To build on existing strengths within the community and address diverse preferences of health care recipients, the **PORT priorities** are to:

- Advance an ethos of dignity
- Advocate for resources & services within the Health Authority
- Improve coordination of care among providers & agencies
- Offer bereavement support
- Offer education to support the provision of high quality care
- Advance research relevant to the above priorities

For **further information** about PORT, to book a workshop, or to consult about a client, please contact one of the following:

- **Grey** Showler or **Caite** Meagher, Cool Aid Society 250-385-1466
- **Kristen** Kvakic, AIDS Vancouver Island 250-384-2366
- **Caelin** Rose or **Lucie** Mattar, Victoria Hospice 250-370-8715
THANK YOU TO EVERYONE FOR MAKING THE DAY SUCH A SUCCESS!