Interim report for SE Health Community Enterprise

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PORT Partners

PORT is a partnership between Victoria Cool Aid Society, University of Victoria, and Island Health. PORT is part of Equity in Palliative Approaches to Care (ePAC), a community collaborative informed by a research program led out of the University of Victoria. Members of the collaborative work together to conduct research with local, national and international partners, and develop resources and tools, programs, and services aimed at improving access to quality care for people facing the end-of-life and who also face inequities like homelessness, poverty, isolation, racism, and stigma.

Funders

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Acknowledgements

We acknowledge with respect the Lekwungen peoples on whose traditional territory the university stands and the Songhees, Esquimalt and WSÁNEĆ peoples whose historical relationships with the land continue to this day.

With thanks and gratitude to all the people who have entrusted PORT to provide services, partners, and funders who have made PORT a reality. Thank you to Carren Dujela, MA, Project Coordinator, Institute on Aging & Lifelong Health, who supported the data analysis for this report.
Who does PORT serve?

Donald
Providers of Victoria’s Palliative Outreach Resource Team (PORT) met Donald a few months ago by way of a nurse and a housing support worker in the community. He was a 66-year-old man living with Stage 4 lung cancer and living in a single-room occupancy hotel with no elevator. Donald had no primary care physician but did access home care nursing though continuity of nurses was minimal. On a home visit, a casual nurse noticed Donald was having difficulty getting up and down stairs. He was socially isolated, unable to manage the stairs and he was in pain, short of breath and not eating. A joint visit between the PORT nurse and a housing support worker was made.

While Donald did not want to be registered with Hospice, the PORT physician and nurse conducted a full consult and obtained a prescription for morphine, which was delivered to his door that afternoon. PORT documented his goals of care on the medical record, filled out a Medical Orders for Scope of Treatment (MOST) form, and identified family living in eastern Canada. They arranged an appointment at the Cancer Agency along with transportation to it, as well as a chest x-ray to see the progression of his cancer.

Two days later, Donald went to the emergency room with a blood clot and died. Through PORT intervention, Donald experienced the last few days of his life without pain with plans for his care in place. And because his family was identified and documented on the medical chart, he was able to call his family to say goodbye before he died.

Daisy
Daisy is a 41-year-old woman who was diagnosed with rectal cancer 2.5 years ago. After surgery, she experienced barriers to ongoing treatment due to transportation challenges and the perception that she was homeless/unstably housed. She was admitted to hospital for cancer treatment and spent most of her nights in acute care with pain and symptom management issues in the year prior to PORT.

An acute care social worker referred Daisy to PORT. Daisy was discharged from hospital and accessed PORT consultation through the Cool Aid Community Health Centre. PORT connected her with a pharmacy, arranged medications to be delivered to her home, and registered her with Hospice. After a month of building rapport and relationships with Daisy, the PORT nurse referred Daisy to Community Health Services and conducted a joint visit with the home care nurse. The PORT physician worked alongside her oncologist to consult on treatment and pain and symptom management issues.

With trusting relationships and bridges among service providers built, home care nursing did their first lone visit with Daisy. PORT services pulled away, making room for mainstream home care services. In the three months that Daisy has been with PORT, she has had no acute care admissions and is now receiving cancer treatments and having her pain and other symptoms adequately managed.
History of PORT

In 2011, a group of Victoria downtown service providers began an informal collaboration to improve access to, and quality of, palliative care for people who are nearing end-of-life (EOL) and who live on the street or are housed unstably. The rationale for the collaboration was rooted in service providers’ experiences of witnessing undignified deaths among people who were stigmatized and marginalized. For Caite Meagher, a nurse at Cool Aid Community Health Centre, it was witnessing an 89 pound homeless man who was dying, HIV positive, living with mental health and substance use issues, with nowhere to go at the EOL.

In 2013, this collaborative, known as the Palliative Outreach Resource Team (PORT) approached UVic Nursing Professor, Dr. Kelli Stajduhar to help them document the experiences of people who are homeless and living with life limiting conditions in Victoria. Since then, PORT and the research team have been leading work to make visible the health and social needs in populations positioned as structurally vulnerable, building capacity among service providers providing care, and advocating for better quality care. Dr. Kelli Stajduhar and team’s research and resultant report, Too little; too late: How we fail vulnerable Canadians as they die and what to do about it illustrates barriers and facilitators to care at EOL for structurally vulnerable people in Victoria.

After 8 years, and as a result of advocacy, research, community partnerships, and planning, and in line with report recommendations and promising models of equity-informed palliative care for homeless and vulnerably housed people in other Canadian provinces, two years of funding from Saint Elizabeth (SE) Health Community Enterprise was secured to develop PORT clinical services. The purpose of the SE funds was to develop and implement the clinical service of PORT, evaluate it, and initiate an ongoing program of research to inform health services and policies related to care of people who are structurally vulnerable and at the EOL in Canada.

PORT Development and Launch

Key stakeholders (e.g., University of Victoria, Cool Aid Society, Island Health Palliative & End of Life Program, Island Health Community Health Services) began meeting in January 2019 to develop the infrastructure for PORT. Key research findings from the Too Little, Too Late report were reviewed to inform program development, develop program goals, intake criteria, referral processes, transitions in/out of PORT, staff roles and support, job descriptions, partners, and evaluation indicators. A PORT nurse and physician were hired and PORT officially launched on September, 19 2019. Community members and partners held a press conference and received media representation from local
and provincial news outlets, recognizing PORT funders (see appendix for full listing).

**PORT Structure and Operations**

PORT is a partnership between the University of Victoria, Island Health, and the Victoria Cool Aid Society and receives funding from SE Health Community Enterprise and the Island Health Palliative Care and End of Life Program. PORT consists of a palliative nurse consultant 0.6 FTE and a palliative consultant physician 0.3 FTE.

As a consultation-based mobile team PORT’s aim is to understand the goals of clients and work together with existing community partners and resources to help ensure equitable access to the services that will help make their clients’ goals a reality.

The goals of PORT are:

1. To improve the quality of, and access to, palliative care for people who are structurally vulnerable and their chosen supporters;
2. To educate, support, build capacity among healthcare providers and in inner city health, housing/shelter, and social services on palliative approaches to care for people who experience health inequities;
3. To improve coordination of palliative care among providers and agencies as it relates to structurally vulnerable populations;
4. To bear witness, capacitate, and support the whole person who is dying and their chosen family including biological and street families, and service providers;
5. Provide resources, direction, and bereavement support to people caring for structurally vulnerable people at end of life;
6. To advocate for accessible, high quality, upstream, integrated palliative care for structurally vulnerable populations; and
7. To advance the body of knowledge for palliative care in structurally vulnerable populations.

PORT is designed to create a low-barrier referral process. Anyone can refer to PORT including people with life-limiting conditions, their friends and family, and service providers. PORT does not have a life expectancy requirement.

PORT operates out of the Cool Aid Community Health Centre but services are provided to anyone who fits the criteria (they are not required to be a Cool Aid client). If the client is not ‘attached’ to a primary health care provider, Cool Aid Community Health has the capacity to take the person on as a client. The eligibility criteria for the PORT program are:

- Life-limiting condition (e.g., cancer, organ failure, advanced COPD) AND
- Difficulty accessing mainstream palliative care services AND
- Living within the geographical scope.

Upon receiving a referral, a PORT member will contact the referral source and, with consent of the individual, investigates their
medical situation and context and completes a thorough assessment. The assessment and conversations about Goals of Care and client priorities may take place over several sessions due to the necessity of building trust with clients who have had poor experiences with the health care system. Barriers in communication (e.g., no phones) and competing priorities (e.g., food, shelter) add greater complexity, and require a flexible and mobile approach.

In addition to this work, PORT also works to develop understanding and build capacity within the community to support the identification of palliative needs and delivery of palliative care to individuals experiencing structural vulnerability. PORT and members of the ePAC collaborative (see below) routinely respond to requests for education to the inner city community, and as other educational and conference-based opportunities emerge, PORT is eager to be involved and help spread the word on equity-informed palliative approaches to care.

Supporting PORT are research projects led by Dr. Kelli Stajduhar and the Equity in Palliative Approaches to Care (ePAC) team (see www.equityinpalliativecare.com).

With funding from the Vancouver Foundation, CIHR and the Canadian Cancer Society Research Institute, the UVic-led team is building capacity with people who live and work in the inner city to identify and support those who could benefit from a palliative approach to care. The PORT physician and nurse are part of an “action team” that meets every 2-3 weeks to build relationships with inner city workers (e.g., housing, shelter, outreach, peer) from seven organizations (Cool Aid Society, Pacifica Housing Society, Together Against Poverty Society, AVI Community Services, SOLID, Portland Hotel Society, and the Island Health Palliative & End of Life Program). Engagement with this group has proven to be an effective site for education and referrals for the PORT service.

From Nov 2018-Dec 2019, our Inner City Action team met 18 times and carried out 12 interventions in the larger community to build awareness and knowledge around death and dying in inner city settings. For instance, members of the Action Team have held Advance Care Planning workshops in shelters and presented to the local hospital social workers about palliative care in the context of inequity.
About this analysis

Since the launch of PORT, PORT has served 47 people. With consent, intake information is collected from all people who enter PORT. Upon service completion, PORT practitioners track service use data. Therefore, our analysis is offered in two parts. **Part 1** consists of demographic and service utilization information for the whole group of PORT clients. This analysis is based on the **43 people** who consented to their data being shared for evaluative purposes. **Part 2** consists of demographic and service utilization data for the **18 people** who PORT has served and who have since left the PORT service due to death or other reasons that will be explained more thoroughly in Part 2.

**PART 1**

PORT has served a total of 47 people to date. Analysis in Part 1 is based on the 43 people who consented to have their data shared for the purpose of evaluation. The average age at time of referral to PORT was 59 years old. Sixty eight percent of PORT clients are male and 16% identify as Indigenous.

**Housing Status**

On entry to PORT, 19% percent of clients were living unsheltered in cars, tents, or on the streets. Thirty percent lived in supportive housing and 7% were living in sheltered, transitional or temporary housing. Seven percent were living in market housing with a housing subsidy. One individual (2%) was living in the hospital due to no other housing option, and one (2%) in assisted living. Twenty eight percent were living in independent, market housing, without housing supports.

**Source of and Reason for Referral to PORT**

Seventy percent of the referrals to PORT came from health care providers while 25% came from community care providers (e.g., housing, shelter, harm reduction, peer workers); 5% came from family members (family of origin and ‘chosen’). These numbers may be reflective of the challenges that health care providers experience in providing palliative approaches to care in the contexts of social and structural inequity (e.g., poverty, homelessness, mental health and addictions issues) and may point to a need for further education and capacity building for health care providers. The number of referrals from community providers (e.g., housing, shelter, peer workers) is encouraging and likely a result of PORT’s integration in the ePAC action team.
There are often multiple intersecting reasons for PORT referral but the primary reasons include declining health/function (80%), pain and symptom management (72%), barriers to accessing services when on a palliative trajectory (75%), and unstable or inappropriate housing (26%). The average number of days from referral to assessment was 11 days.

The reasons for PORT referrals are varied and reflect PORT’s specialty in the intersections of palliative care and inequity. Some referrals to PORT are coming from people who have little access to the health care system. For instance, one PORT client was living in his car and one in his tent – both had little contact with the system. There are others who have had admissions to hospital and emergency, but have not been met with a palliative approach to care.

The primary palliative diagnosis of PORT clients includes cancer (44%), end stage liver disease (12%), chronic respiratory diseases (e.g., COPD, asthma; 9%), cardiovascular disease (e.g., heart failure) (7%), and renal failure (5%).

Twenty-one percent of PORT clients had other primary diagnoses such as chronic infections, and 5% were unknown. Current research in the community is revealing how typically treatable conditions “become palliative” in contexts of poverty, homelessness and unstable housing, stigma and discrimination. This points to the need for continued palliative education to ensure that people who have these conditions get proper care, treatment, and support through their lifespan.

PORT clients are characterized by a high disease burden with co-morbidities including chronic pain (54%), frailty (42%), chronic respiratory disease (37%), Hepatitis C (33%), liver disease (28%), cardiovascular disease (23%), arthritis (19%), diabetes (19%), renal disease (14%), cancer (5%), and HIV/AIDS.
(5%). Approximately half (51%) of PORT clients are living with a mental illness, and a further 72% live with a substance use disorder. These co-morbidities are striking and speak to the need for approaches that focus on quality of life, pain and symptom management, and making future health care plans. The client population and work is complex and it is no surprise that PORT seems to be filling an important gap in a silo’d health care system.

The average Palliative Performance Scale score on admission to PORT was 50-60% indicating reduced ambulation, activity and self-care ability, and that food and fluid intake and consciousness levels may still be normal or be reducing.

**Hospital Utilization Prior to PORT**

Currently, we do not have comparable data on hospital utilization rates pre-and-post PORT. In the year prior to PORT, the average number of admissions to the emergency room were two per person and the number of hospital admissions were also two in the year prior to PORT. The average number of nights spent in hospital per person in the year prior to PORT was 33 nights, with the maximum number of nights being 192.

**Care Planning and Decision Making**

Preliminary analyses indicate that the population PORT is seeing are people who have not yet received or benefited from a palliative approach to care. Upon entry to PORT, 79% did not have an Advance Care Plan. Almost half (49%) had a Medical Orders for Scope of Treatment (MOST)\(^1\), C2 indicating that their medical wishes were to attempt to extend or preserve life through the use of critical care interventions including CPR, defibrillation and/or intubation.

Substitute decision makers become important in the event that people are unable to communicate or make decisions for themselves. At the time of referral to PORT, a substitute decision maker was identified for 56% of the clients. However, 44% percent of PORT clients did not have a substitute decision maker or it was unknown. In the context of family estrangement and barriers to communication (e.g., access to a phone) and transportation, PORT is finding it difficult to connect with someone who is willing and able to take on this important role. Of those who did, decision makers included family of origin (54%), partners (25%), friends or chosen family (17%), and in one case (4%), the PORT physician became the person’s substitute decision maker. Preliminary findings stress the important role of Advance Care Planning in care for people with life-limiting conditions in the contexts of inequity.

**Support from Primary Care**

Levels of primary care support for PORT clients varied. In 72% of the cases, the person had a primary health provider involved in their care. These providers were predominantly located at the Cool Aid Community Health Centre (74%), an inner city primary care clinic. Other PORT clients had a regular primary provider at a clinic other than Cool Aid (26%).

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\(^1\) MOST is a form filled out by a physician which provides directions for scope of treatment based on a person’s wishes. Values (C2, C1, C0, M3, M2, M1) range from critical care (C2) to comfort care (M1).
For almost a quarter of PORT clients who did not have a primary care provider upon referral to PORT, the PORT physician has taken on this role. Due to the high number of clients who have primary care providers, much of the PORT physician’s work involves building knowledge and capacity with other physicians about the intersections of addictions medicine, structural vulnerability, and a palliative approach to care.

**PART 2**

**Disposition of PORT Clients**

Of the 43 PORT clients who consented to sharing their data for evaluative purposes, 18 people have been discharged from PORT. The following analysis is on the 18 people who have finalized their involvement with the PORT service.

The average number of days on the PORT service was 37. Of the 18 discharged clients, eight died and the other 10 were deemed no longer in need of PORT services and referred to other services. In one case, after a thorough assessment, PORT supported the client to get registered with Victoria Hospice and documented their goals of care on the medical record, but because the client was well supported by community health services, PORT’s services were no longer needed. In other cases, the client was well supported in the community and/or by the medical system and there was no need for PORT involvement. For instance, a person was discharged from PORT because they had no clear palliative diagnosis along with very active goals of care. The person was discharged after the PORT nurse assessed them and facilitated more appropriate health services.

**Care Planning and Decision Making**

Goals of care conversations were had and documented on the medical record for 100% of the clients who received PORT services.

By the end of their involvement with PORT, a substitute decision maker was identified for all but one of the eighteen clients (94%). Substitute decision makers included individuals from the family of origin (47%), partners (24%), friend or chosen family (24%), and the characteristics of one were unknown.

**Figure 4: Relationship of the substitute decision maker to the PORT client**

**Health and Social Service Use**

Eight of the 18 (44%) PORT clients were registered with Plan P benefits and the others were deemed ineligible because their uncertain illness trajectories. Of the available family caregivers, none were eligible for Canada’s Compassionate Care
Benefit predominantly because they did not meet the minimal employment requirements. This finding points to the need to critically examine eligibility criteria for government supports that could benefit caregivers in the context of inequities.

Eleven people received medical equipment with 64% coming from the Red Cross, 9% from the Ministry of Health, and 27% coming from both. Red Cross requires that a person has a home for equipment, so clients without stable housing relied on equipment from other channels (e.g., borrowing, donations).

Preliminary analyses suggest that even with the support and advocacy of PORT, Community Health Service (CHS) use for PORT clients remained low. Of the clients who accessed PORT, four (22%) accessed Island Health’s Community Health Services case management services. Three of the 18 clients (17%) received support from the Island Health’s Palliative Care Coordinator. Five clients (28%) accessed social work support from Island Health’s Palliative & EOL Care program and 2 (11%) accessed social work support from Island Health CHS. While 9 (50%) had access to home care nursing, only 3 clients (17%) had access to home support services. Two clients (11%) had access to Physical Therapy and 7 clients (39%) had access to Occupational Therapy. Two clients (11%) had access to a dietitian.

These preliminary findings indicate the need to continue working alongside CHS to ensure that barriers to accessing care are addressed. In addition, while PORT has been developed as a consultation service, it is clear that care coordination is an urgent and primary need for PORT clients. For example, the PORT nurse and physician are frequently filling gaps that would normally be filled by family caregivers if they were available. The PORT nurse and physician often engage in care duties such as facilitating apartment moves to obtain adequate housing for care, securing safe parking spots for clients who live in their cars when they are admitted to hospital, picking up and assembling medical equipment, going to grocery stores and food banks so clients will have food, transporting and accompanying people to appointments, etc. While these activities may be seen as out of scope for the limited nurse and physician time allotted for PORT, they are necessarily elements of care in the context of structural inequities and a lack of family caregiving support. While the ePAC collaborative led out of the University of Victoria is currently supporting the development of volunteer supports for PORT in order to address these gaps, our preliminary analysis suggests the need to develop some care coordination models that will better address PORT client needs.

Hospital Utilization

Of the 18 clients who finished their involvement with PORT, the average number of emergency room visits while on PORT was less than 1 (0.44) and the average number of nights spent in hospital per person was seven. While we cannot yet make any inferences on hospital utilization rates, these preliminary data indicate that the PORT service may reduce hospital utilization rates.

Circumstances Surrounding PORT Deaths

The average age of death of PORT clients was 63 years old. Their MOST values at time of death were M1 (14%), M3 (43%), C0...
(14%), and C2 (29%) indicating some success in modifying active goals of care. PORT practitioners have been surprised by the number of people who want “full code” in spite of having a strong aversion to the hospital. This mirrors research that indicates that homeless people often want “full code” because they do not want to be “written off” by health care professionals.

Of the eight people who PORT has supported until death, three were supported to die at home, four died in acute care, and one died in Hospice. While two people requested Medical Assistance in Dying (MAiD), only 1 person had MAiD administered. In 7 of 8 cases (88%), people died in their place of choosing. For the individual who was not able to die in his place of choosing, he decompensated quickly in hospital and died while awaiting long-term care.

PORT offered bereavement support to caregivers in all but 2 deaths where there was no one to offer support to. Bereavement support was offered to partners, family of origin, health care providers, and community providers. PORT practitioners have identified bereavement support as an important aspect of palliative care to expand in the community. Particularly in light of the deep and compounding grief experienced by people who live and work in the inner city, we are looking for opportunities to expand this collective grief and loss support work.

**Next Steps**

With a current case load of 29 people, PORT practitioners are continuing to identify and meet the care needs of people who are living with life-limiting conditions in the context of inequity. They are strengthening their relationships with health and community providers to not only provide direct care, but to build capacity in the system for quality care. This is happening alongside UVic-led research to build capacity for palliative approaches to care in the inner city.

In the first four months since the initial launch of PORT, it seems as though PORT is meeting its stated goals. Priorities beyond direct client care include a focus on examining the need for care coordination and how that is conceived, developing a volunteer components to support PORT activities, expanding bereavement support, and gaining a deeper understanding of service gaps that would enable people to be supported to be cared for and die in the community if that is their wish. In addition, discussions on the sustainability of the PORT program beyond the initial SE catalyst funds are being explored.

**PORT Recognized**

**Scientific and Community Conferences**


- Stajduhar, K. I. (2019, Oct 13). *Provocations on Privilege and Palliative Care: Are we meeting our core mandate?* Keynote address at the 6th International Public Health
Palliative Care Conference, Blue Mountains, NSW, Australia.


**Education and Capacity Building**

- Leahy, K. & Black, F. (2019, July 2, 9; 23; Aug 6; Sept 3, 17; Oct 1, 22; Nov 26; Dec 10). Participation in the ePAC Inner City Action Team meetings to provide support to inner city worker and connect around PORT referrals, Victoria, BC.
- Black, F. (2019, November 20). Presentation on PORT and care for structurally vulnerable populations at Victoria Hospice’s Medical Intensive Course, Victoria, BC.
- Black, F. & Leahy, K. (2019 November 12-13). Attendance at Equity in Palliative Approaches to Care (ePAC) Visioning Retreat, Sidney, BC.
- Leahy, K. (2019, October 9). Presentation about PORT at Island Health’s Victoria Community Health Services monthly nurses meeting, Victoria, BC.
- Leahy, K. (2019, September 26). Presentation about PORT at Island Health’s Victoria Community Health services monthly team meeting, Victoria, BC.
- Leahy, K. & Black, F. (2019, September 4). Presentation about PORT at Portland Hotel Society’s team meeting, Victoria, BC.

**Media**


**ePAC newsletter and social media**

- PORT has been featured in the ePAC Newsletters Summer 2019 (https://mailchi.mp/00a37d0b5099/epacnews)
PORT has been featured through the ePAC twitter account (@access2care) and other PORT partners (e.g., Cool Aid Society, Victoria Hospice Society, Island Health, UVic) multiple times since launch.