



Palliative Care Learning Cycle Report

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Document Purpose

This report summarizes the ISU’s Palliative Care Learning Cycle, completed in 2021. It includes findings from the rapid literature review, stakeholder interviews, and constructive workshop, including suggestions for next steps. The materials here are provided to help inform further community-based discussions around enhancing interprofessional collaboration and improving team-based care for patients with palliative care needs.

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1. Introduction

The COVID-19 pandemic has brought forth many challenges to both primary and palliative care practices that could impact the quality of care received by patients. Discussions between the Innovation Support Unit (ISU) and Dr. Amrish Joshi, a Palliative Care Physician in Richmond, British Columbia (BC), led to the development of this project to address the following overarching questions:

How has the COVID-19 pandemic affected the care of adults with palliative care needs in BC and how could community primary care and palliative care services be enhanced to better support these patients?

2. Approach

To explore this question, the ISU sought to learn about palliative care needs in BC, the integration of palliative care and primary care services, as well as changes brought forth from the pandemic within BC communities. We aimed to engage with stakeholders, including palliative care providers, primary care providers, and patient representatives to learn from different perspectives and to understand how palliative care needs differ across the BC population. A standard ISU 'learning cycle' approach was used, as illustrated in Figure 1.

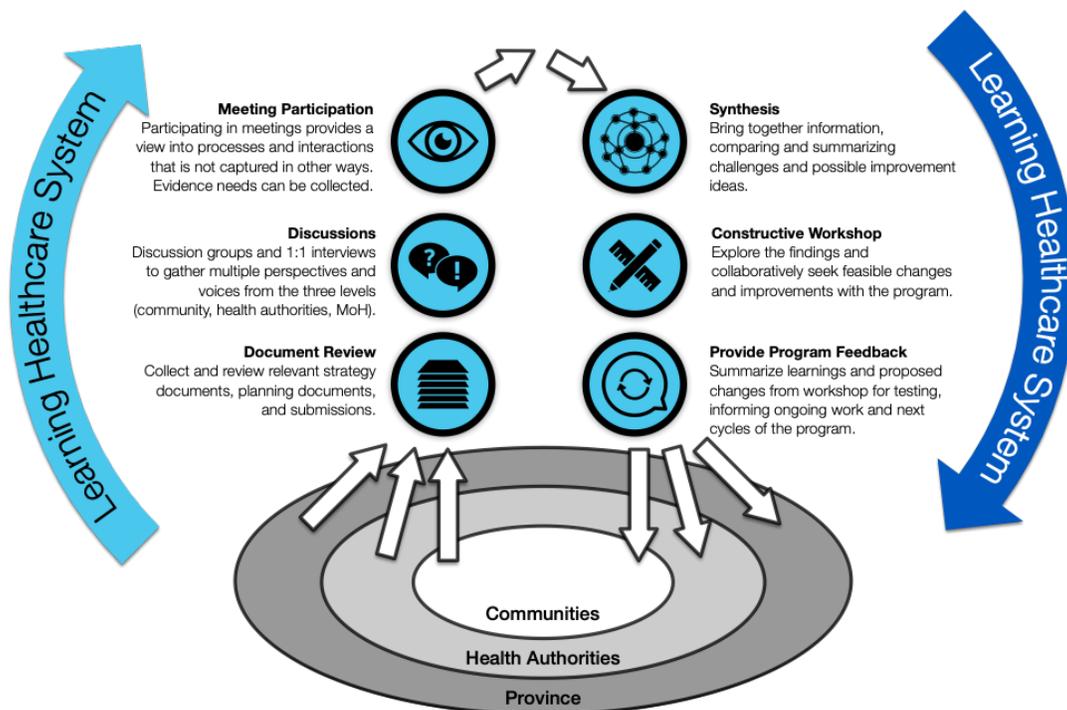


Figure 1: Learning Cycle approach

The learning cycle began in November 2020 with a rapid review of palliative care policy documents across Canada, the United States of America (USA), the United Kingdom (UK) and Australia. In addition, two international academic literature searches were conducted in PubMed, CINAHL and the Cochrane Library, focused on: 1) access to palliative care services (review articles published from January 2015 to November 2020), and 2) primary and

community palliative care related to COVID-19 (articles published from March 2020 to November 2020).

Between December 2020 and January 2021, the ISU engaged 13 stakeholders (representing primary care, palliative care and patients) from across the province in a series of one-to-one semi-structured interviews. The interviews were conducted via Zoom (recorded with permission) and lasted approximately 45 minutes each. Thematic analysis identified key themes and the findings, in conjunction with literature review data, informed the constructive workshop.

Eleven community primary and palliative care providers in Richmond (Vancouver Coastal Health) and across Fraser Health participated in the workshop on the 18 February, 2021, including: palliative care physicians, palliative clinical resource nurses, primary care family physicians, a medical oncologist, a social worker, and a community pharmacist. The ISU Team Mapping Method,¹ was adapted to explore how team-based primary and palliative care approaches could be improved for supporting patients and families with palliative care needs. Two patient personas, Murphy and Olivia were used to facilitate discussions (maps are available in Appendix 1 at the end of this document).

3. Recommendations

The high-level recommendations from this learning cycle are outlined in this section. Further details on the findings from the literature review, interviews and constructive workshop are included in Sections 4-6, and summarized in Section 7.

3.1. System

- **Improve Equitable Access to Telehealth**
The increased use of telehealth in response to the pandemic restrictions was largely welcomed by providers and patients, however equitable access was an issue. If the use of telehealth is to continue post-pandemic, this needs to be supported with adequate training in video technologies for providers and patients, as well as innovative solutions for ensuring that all communities and individuals have equitable access.
- **Improve Consistent Information Sharing**
With the multiple services and providers involved in community-based palliative care, systems need to be in place to allow efficient and timely sharing of relevant patient information. Access to advance care plans is particularly important to ensure that patients and families can be supported appropriately at end-of-life, with primary care family physicians in the best position to initiate and start advance care planning.

3.2. Community

- **After-hours Care**
The pandemic prompted a shift from inpatient hospital and hospice care to home-based end-of-life care. This change highlighted the challenges in providing after-hours (evening and weekend) community care with the limited resources available. Homecare nurse visits and shift care nursing were seen as important for supporting

home-based after-hours care, as well as the availability of advance care plans to assist on-call palliative care physicians in supporting patients and families.

- **Patient/Family Navigator Role**

Families, homecare nurses, and social workers often share the role of navigator; however, workload may impact the ability of homecare nurses or social workers to fully support this role, and while families may be able to advocate for patients, navigating an increasingly complex network of providers while caring for a family member at the end-of-life is likely too challenging to manage. Establishing a focused palliative care navigator role may be beneficial for coordinating community care across multiple providers and settings, particularly with coordinating access to patient medical records and advance care planning documents.

3.3. Team

- **Integrated, Cross Team, Rapid Rounds**

Bi-weekly rapid rounds were identified as a useful coordination tool within homecare and oncology teams. Extending this model to include primary care and other providers may be an option for enhancing collaboration and communication, while recognizing the challenges associated with the fluidity of team membership.

3.4. Individual

- **Increase Patient and Family Knowledge (particularly for end of life at home)**

Enhancing patient and family educational resources regarding who to contact for specific issues of care (i.e., after-hours support) may help to resolve some of the uncertainty faced by patients and families in accessing palliative care, particularly at end-of-life. Resources to support families in their role as caregiver may also improve the experience of patients and families when choosing end-of-life care at home.

4. Literature Review

Palliative care is “an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness”.² In Canada, the Framework on Palliative Care outlines a collective vision for palliative care, to ensure that “Canadians with life-limiting illness live well until the end of life”.³ The framework includes 10 guiding principles that are considered key in providing high-quality palliative care, and four priority areas to guide short, medium, and long term action in palliative care:

1. Palliative care training and education for health care providers and other caregivers;
2. Measures to support palliative care providers and caregivers;
3. Research and the collection of data on palliative care; and
4. Measures to facilitate equitable access to palliative care across Canada.

A 2018 report by the Canadian Institute for Health Information highlighted that very few Canadians receive home-based palliative care in their last year of life and that earlier integration of palliative care and availability of community palliative care are important for supporting end-of-life at home.⁴ The BC guidelines for primary care providers also highlight

the importance of advance care planning and establishing goals of care in supporting patients and their families.⁵

There are gaps in palliative care seen internationally. In the UK, approximately 1 in 4 individuals do not receive palliative care at the end of life.⁶ This has resulted in calls for increased commitment to palliative care equity and collaboration to ensure adherence to palliative and end of life care strategies, and the development of more sophisticated measures of palliative care policy implementation.⁷ Palliative care is also not well represented in the USA, due to training⁸ and financial^{9,10} limitations, although there is policy support for improving palliative care access¹¹⁻¹⁴ and initiatives are in place to increase palliative care access across the country.^{15,16}

In contrast, Australia has been one of the most highly rated in international assessments of quality of palliative care services,¹⁷ with integration of palliative services available within almost every healthcare setting in addition to home-based outreach and specialist-based services¹⁸. This quality can partly be attributed to the early adoption of national palliative care priorities involving the collaborative efforts of all governments, providers, and community-based organisations, as well as increasing palliative care awareness to both the public and service providers.¹⁹

Despite these policies and commitments there are still disparities in equitable access to palliative care services, particularly for medically underserved and vulnerable groups, including those of lower socio-economic status, living in rural areas, and with intellectually disabilities,²⁰⁻²³ and a need to provide culturally competent and culturally safe palliative care for Indigenous patients and families.²⁴ Barriers to palliative care have been associated with lack of education and training,^{20,25,26} limited funding,^{20,25} fragmented services,²⁵⁻²⁷ communication issues,^{20,21,28} and lack of awareness or knowledge about palliative care services,²⁵⁻²⁸ while facilitators focus on family involvement,^{21,27,28} integration of cultural practices,^{21,27,28} availability of skilled staff,²⁶ coordination and flexibility,^{20,26} as well as support for patients and healthcare professionals.²⁶

The COVID-19 pandemic has highlighted and likely exacerbated existing challenges in care integration,²⁹ yet has also created opportunities for palliative care access, particularly through the use of telehealth to support patients at home and strengthen family involvement in care.³⁰⁻³⁴

The '4S' model, proposed by Downar et al (2010),³⁵ was frequently cited in considering the availability of Stuff, Staff, Space and Systems and how this impacted palliative care services.^{31,36-39} Systems had to adapt quickly, with a need for consistent and timely communications in relation to protocols, policies and public health measures and a flexible approach to supporting patient and families in response to the changes. A shift was observed, from providing inpatient hospital or hospice-based care to community settings, with virtual technology used to enable communication and reduce isolation. However, this change in the healthcare space was accompanied by concerns related to workforce capacity (staff shortages and long hours), highlighting the need for flexibility, such as moving staff from acute to community settings, to increase the availability of providers. Educating and engaging a range of healthcare professionals was also seen as important in supporting patients and

families, while the availability of personal protective equipment (PPE), medication, equipment and diagnostic tests were a priority when considering the ‘stuff’ required to support palliative care services through the pandemic. Given the changes in care delivery due to COVID-19, we found the 4S model a useful framework for this report.

5. Interviews

We interviewed 13 stakeholders, including: primary and palliative care physicians, managers, palliative clinical resource and specialist nurses, and patient representatives. Four common themes were highlighted from the key stakeholder interviews: **home-based care coordination, family role as caregivers, virtual supports** and **equity**.

Within these themes, the importance of stuff, staff, space and systems were apparent – from the home-based and virtual space that patients, families and providers were navigating, to the equipment, systems and resources required to support this shift in care.

5.1. Home-based Care Coordination

The introduction of visitation restrictions within hospices resulted in patients wanting to remain at home for end-of-life care. While generally viewed as a positive, the shift to home-based care dramatically increased the workload burden of providers (i.e. those providing more home-based care) often without an increase in resources to support this change. Resource shortages and anxiety related to the pandemic highlighted the limited mental health supports for providers and the higher risk of burnout experienced by providers.

Supporting patients and families at home required coordination and communication between various services, which could often be challenging. Primary and palliative care providers both acknowledged the need for better communication and more seamless interaction to connect and exchange information in a timely manner. Flexibility was seen as important in team-based care and having an established relationship between providers often facilitated care coordination. Support from pharmacies was also valuable, such as extending existing prescriptions when waiting on a new prescription, and delivering medication to patients.

5.2. Family Role as Caregivers

The increase in home-based care also relied on families being capable, available and willing to provide care for their loved ones during end-of-life. Administering subcutaneous medications was a notable point of hesitancy in the ability for families to provide care and home-care nursing may not always be available when needed. Fortunately some homecare providers were able to implement the use of automated pumps to remove the requirement for families to inject medications, although this relied on the availability of equipment and staff trained in the set-up and use of the pumps. Where patients and families required additional support, such as shift care nursing or hospice care when the patient started transitioning, a negative COVID-19 test was often required by the hospice prior to admission or by the care team before initiating shift care in the home. Unfortunately, COVID-19 test reporting can be a time-consuming process when rapid testing is unavailable and sometimes results came too late to enable these services. Pandemic restrictions also altered family and community experience of supporting loved ones and the cultural and spiritual traditions associated with end-of-life, which may have lasting impacts on their grieving process.

5.3. Virtual Supports

Given the requirements to limit direct contact between providers and patients, telehealth and other virtual care mediums were increasingly used. Phones were the most commonly used virtual health tool. Overall, this change was seen as positive, with providers reporting favorable interactions with the technology, noting that they were able to take on more consults in a variety of (private) locales and improve patient relations through increased frequency of contact or 'check-ins'. Providers reported that patients were positive about telehealth, sometimes preferring it to in-person visits, particularly where they were reluctant to leave the house for medical attention due to concerns about COVID-19. However, these technologies were not without their limitations. When considering real-time communications, given phone consultations were the more commonly used method of contact for providers, non-verbal messaging was missed and they also lacked the visual component necessary for some of the more complex and difficult consultations, such as those requiring physical assessment, highly emotional conversations, or those requiring an understanding of the patient's home environment. These issues were somewhat mitigated by telehealth solutions such as Zoom and Doxy.me, and the accessibility and acceptance of these technologies was greatly increased by the pandemic. There was a consensus among providers that virtual care consultations were 'here to stay'.

Other technologies related to virtual health were mentioned, albeit to a lesser degree. These included the adoption of an electronic faxing services for prescriptions, digital surveys in place of patient forms for initial consults, and the use of email rather than fax to obtain signed forms. Some providers mentioned how they were unable to access health authority pandemic resources and often had to rely on alternative sources like Facebook and YouTube to receive necessary education (e.g., putting on PPE without assistance when conducting a home visit).

5.4. Equity

The increased use of telehealth highlighted inequitable access to care. Outside of connection issues, telehealth solutions can be expensive and inaccessible to those in lower income areas, require technological knowledge not always known by providers or patients, and have bandwidth requirements beyond those in remote regions. First Nations communities, elderly patients, homeless populations and those with English as a second language were seen as particularly vulnerable to the inequities arising from telehealth. Fortunately, some health authorities have begun providing dedicated phones and tablets to patients as well as increased education for patients and providers to address some of these accessibility issues.

6. Constructive Workshop

Based on the interview findings, and informed by the rapid review, the ISU identified four areas of interest to further explore around providing and coordinating community-based care for attached and unattached patients with palliative care needs:

- Regular hours care;
- After-hours care;
- Support for early palliative care needs (>6 months);
- Use of telehealth.

To explore these areas of interest and how team-based primary and palliative care approaches could be improved for supporting patients and families with palliative care needs, the ISU organized and facilitated a constructive workshop using a modified Team Mapping¹ approach. Eleven community primary and palliative care providers in Richmond and across Fraser Health participated, including: palliative care physicians, palliative clinical resource nurses, primary care family physicians, a medical oncologist, a social worker, and a community pharmacist.

Two personas (Murphy and Olivia) were developed and specifically tailored to trigger discussions on the numerous unique roles and associated in-person or virtual tasks that would be important in supporting patients with palliative care needs in the community. Below is a summary of the findings from the Team Mapping session. The two team maps that were created are included in Appendix 1.

6.1. Care Coordination

The Team Mapping highlighted the many people and providers involved in supporting patients with palliative care needs in community. This can lead to a high degree of complexity regarding care process for patients, which is further exacerbated by the multiple, separate, disconnected EMR systems and paper records used by care providers and in different care settings. Use of these independent systems of communication and record keeping makes it difficult to share complete patient information. When multiple providers and teams are involved in a patient's care, there can be misunderstandings around who is monitoring and coordinating care for the patient, resulting in the patient 'falling through the cracks'. This confusion is also shared by the patient and their family, as it can be difficult for patients and families to know who to contact for help and advice (oncology team, home care, community-based palliative physician, family physician or other provider), further fragmenting care coordination. Where patients require medication, responsibility for prescribing is often shared between the family physician, palliative physician, medical oncologist and/or Pain and Symptom Management Clinic team, while dispensing can involve the BC Cancer Agency pharmacist, hospital pharmacist and/or community pharmacist.

6.2. After-hours Care

After-hours care options were discussed, with recognition that evening and weekend care coverage is limited. For non-emergency advice and information, patients or families can call HealthLinkBC (8-1-1). Homecare nurses can also support patients and families with home visits after hours or with specific in-home nursing supports available, including 48 hours of home care for symptom management and assessment; or 120 hours of home care shift nursing to support end-of-life care at home. However, finding experienced nurses to work during the weekend is challenging, and support for the homecare nurses is reduced compared to weekday hours (8:00am to 4:00pm), where Palliative Clinical Resources Nurses are available. Although on-call palliative physicians are available after-hours and nurses have access to a 24-hour advice phone line, supporting a patient at home can be difficult if an advance care plan has not been established (in setting the need for palliative care services), or the patient is not known to the palliative care services. In these situations it may be possible to support patients at home, with subsequent follow-up with the palliative care team or primary care provider during regular hours, however if the community palliative team are unable to ascertain previously documented goals of care, a patient may have to be re-

directed to the acute care setting. Hospice admissions in Richmond are always planned and they do not admit emergently out of hours, or on the weekends.

6.3. Advance Care Planning

A first step in providing palliative care services is for the patient and families to accept the end-of-life trajectory and agree to a palliative approach to care. In the Team Mapping session, advance care planning and establishing the goals of care were identified as crucial for palliative care services to support patients and families. Advance care planning should be started early, preferably with a family physician, but continued as a team effort involving the multiple providers engaged in the patient's care. Virtual options have been useful in facilitating these discussions with patients and families, although it was recognized that cultural differences in perspectives on palliative care, and hope for further treatment can make these conversations difficult to initiate. It was identified that communicating and sharing up-to-date care plans between providers can be difficult and would benefit from being more coordinated and accessible. Advance care plans are also highlighted in the pandemic given the higher risk for mortality in the older population.

6.4. Cultural Sensitivity

Cultural barriers were recognized in palliative care as well as a lack of resources to support patients, for example: providers who speak their language. While interpreters are sometimes available, families are often relied upon to act as interpreters. Within Asian communities there can also be a resistance to accept a palliative prognosis based on beliefs that if the individual is made aware of their diagnosis, they will decline rapidly. This could be exacerbated with a mostly virtual and more uncoordinated system brought about by the pandemic.

7. Summary

The results of this learning cycle highlight the challenges in coordinating care between multiple providers when supporting patients and families with palliative care needs. The interviews reflected findings from the literature review in the shift towards community-based palliative care during the pandemic, with providers highlighting the challenges encountered in communicating and coordinating care between multiple services and the increased burden on families as caregivers. While telehealth was often seen as a positive and welcomed by providers and patients, it also highlighted inequities in access to care, which need to be considered and mitigated if telehealth is 'here to stay'. Through the Team Mapping session, providers were able to visualize how care is currently coordinated in their community and discuss key areas for supporting palliative care services, such as after-hours care and the importance of advance care planning.

The ISU team would like to thank everyone who participated in this project. We hope that this report helps to illustrate the challenges of providing community-based palliative care services and therefore acts to facilitate discussions to identify new ways of working.

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Appendix 1: Team Maps



Gaps

<p>EMR</p> <p>In Fraser Health - 3 EMR systems to record patient info (home health, hospital, oncology services BCCA). Palliative physician has access to all 3 systems but family physicians only have access to what has been sent to them or what they are registered for.</p> <p>Same in VCH except that Care Connect pulls in the info from some of the other systems e.g. PARIS (homecare uses)</p> <p>Richmond Hospital using paper charting. Acute care does not have full access to notes. Community using PARIS. Transition Nurses between Acute and Community Care have access to notes.</p> <p>Homecare don't have access to GP notes (and vice versa)</p> <p>Multiple providers</p> <p>Multiple people involved in care. One team may think that another team is monitoring/ coordinating care (and vice versa) so patients fall through the cracks</p> <p>Ideally attach patients to BC cancer that is local but not always the case. Some patients start at one and transfer to another.</p> <p>Family</p> <p>Family providing/managing subQ meds, personal care. Ensure personal care can be managed by family.</p>	<p>Advance Care Planning (ACP)</p> <p>A lot of ACP can be done virtually and saves a lot of time for physicians, patients and their families - one area that has been facilitated by virtual options</p> <p>Lack of coordinated goals of care between providers.</p> <p>Patients not wanting to talk about ACP. Still wanting further treatment.</p> <p>Goals of care conversations at the family physician office would be most helpful but also see ACP as a team effort involving home health, palliative physician, oncologist etc. Start early on in the journey.</p> <p>ACP information not readily available on Care Connect</p> <p>Encourage communication between care providers - advance care planning between all members of the care team</p> <p>If goals of care conversations have not happened or have not been established the on-call palliative physician would usually refer the patient to hospital for after hours care.</p> <p>If GP cannot be reached, it is easier for the palliative physician if goals of care have been established.</p> <p>Patient end-of-life decline unpredictable at times - may conflict with ACP</p>
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