BC Centre for
Palliative Care

Facilitating Equitable Access to Palliative and End-Of-Life Care for Underserved Populations in British Columbia: Knowledge Exchange Series (2025)

Insights Specific to:

People Living with
Rare Diseases or
Hematological Disorders

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Knowledge Exchange Overview

In Spring 2025, the BC Centre for Palliative Care on behalf of the BC Palliative Care Research Collaborative hosted a three-part virtual **Knowledge Exchange Series** on *facilitating equitable access to palliative and end-of-life care for underserved populations in BC*.

Shaped by research, expert insights, and lived experiences, the series aimed to advance an equity-informed approach to palliative care by sharing stories, highlighting promising practices, strengthening connections between health and community systems, and identifying future directions for policy, practice, and research.

Discussions and activities focused on twelve underserved population groups with limited access to essential palliative and end-of life care services.

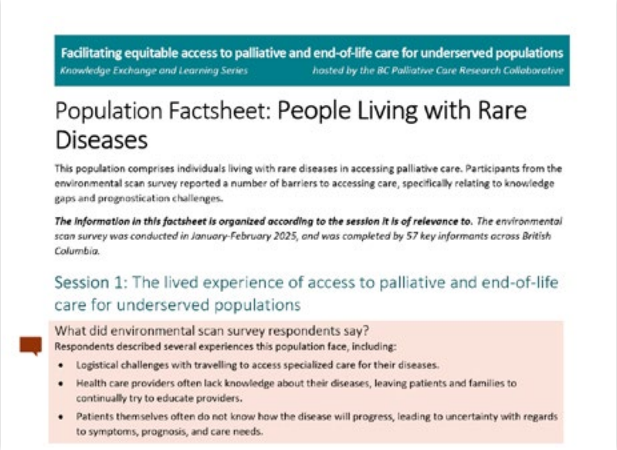
Read the full Summary Report here.

Insights Specific to People Living with Rare Diseases or Hematological Disorders

Insights from the Literature and Key Informants

To inform discussions about **people living with rare diseases or hematological disorders** during the Knowledge Exchange sessions, population fact sheets were developed. The fact sheets summarize key themes from a literature review and insights gathered from key informants through an online survey—highlighting experiences, opportunities, facilitators, and barriers to care.

View the population fact sheets here and here. A preview is shown below.



Facilitating equitable access to palliative and end-of-life care for underserved populations
Knowledge Exchange and Learning Series *hosted by the BC Palliative Care Research Collaborative*

Population Factsheet: People Living with Rare Diseases

This population comprises individuals living with rare diseases in accessing palliative care. Participants from the environmental scan survey reported a number of barriers to accessing care, specifically relating to knowledge gaps and prognostication challenges.

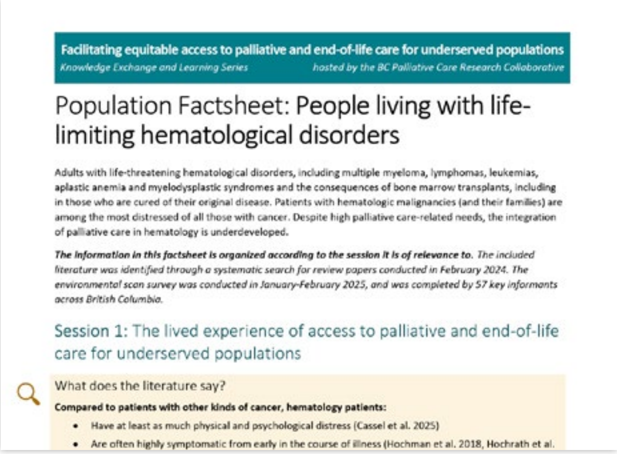
The information in this factsheet is organized according to the session it is of relevance to. *The environmental scan survey was conducted in January-February 2025, and was completed by 57 key informants across British Columbia.*

Session 1: The lived experience of access to palliative and end-of-life care for underserved populations

What did environmental scan survey respondents say?

Respondents described several experiences this population face, including:

- Logistical challenges with travelling to access specialized care for their diseases.
- Health care providers often lack knowledge about their diseases, leaving patients and families to continually try to educate providers.
- Patients themselves often do not know how the disease will progress, leading to uncertainty with regards to symptoms, prognosis, and care needs.



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Population Factsheet: People living with life-limiting hematological disorders

Adults with life-threatening hematological disorders, including multiple myeloma, lymphomas, leukemias, aplastic anemia and myelodysplastic syndromes and the consequences of bone marrow transplants, including in those who are cured of their original disease. Patients with hematologic malignancies (and their families) are among the most distressed of all those with cancer. Despite high palliative care-related needs, the integration of palliative care in hematology is underdeveloped.

The information in this factsheet is organized according to the session it is of relevance to. *The included literature was identified through a systematic search for review papers conducted in February 2024. The environmental scan survey was conducted in January-February 2025, and was completed by 57 key informants across British Columbia.*

Session 1: The lived experience of access to palliative and end-of-life care for underserved populations

What does the literature say?

Compared to patients with other kinds of cancer, hematology patients:

- Have at least as much physical and psychological distress (Cassel et al. 2025)
- Are often highly symptomatic from early in the course of illness (Hochman et al. 2018, Hochrath et al.

Insights from the Knowledge Exchange Series

Key barriers, potential solutions and recommended actions that emerged from discussions on improving palliative and end-of-life care access for *people living with rare diseases or hematological disorders.*

Insights Specific to People Living with Rare Diseases or Hematological Disorders

Barriers

- **Low awareness:** Limited public and professional awareness of rare diseases and their unique needs can result in late referrals to palliative care.
- **System navigation:** It can be challenging for patients and caregivers to navigate the system, especially around when to transition to palliative care and which providers to reach out to for support.
- **Poor communication:** Families often aren't given space to ask questions.
- **Gaps in supports and services:** There is a lack of providers with capacity or time to fully meet the patients' needs, such as guiding them through the palliative care journey.

Solutions

- **Community advocacy and outreach:** Information groups, events, and outreach should be done to raise awareness about palliative care. One idea is to distribute informational pamphlets in pharmacies to help reach a broader audience.
- **Survey patients:** Use tools like the Canadian Problem Checklist to identify patient needs early.
- **Set care standards:** Use accreditation and minimum standards to improve provider knowledge and accountability.

Recommended Action

There is a strong need for better community advocacy to raise awareness about palliative care. Many people only learn about it when they or a loved one are already in crisis, and even then, they often don't fully understand what it involves. Education should start earlier, through community events, information groups, and targeted outreach. Palliative care awareness must extend beyond cancer to include all serious illnesses –including rare diseases.

Insights from the Knowledge Exchange Series

After the Knowledge Exchange Series, participants completed a survey to prioritize the most important research questions and promising solutions for each underserved population.

Due to limited capacity and participants' focus on other populations, the experiences of this group in accessing palliative care were not discussed in Session 3. As a result, this population was not included in the final survey, and no insights were gathered regarding top-rated research questions or potential solutions.

For similar insights on other underserved populations, visit the BC Centre for Palliative Care website here.

BC Centre for Palliative Care

Advancing palliative care through best practices, innovation and collaboration.

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