



Canadian
Cancer
Society



Advancing Health Equity Through Cancer Information and Support Services

Report on communities that are underserved

October 2023

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The following organization completed literature reviews, data and document reviews, and roadmap development and led the stakeholder engagement for the underserved communities project.

Optimus SBR

Organizations in stakeholder engagement

Key informant interviews were conducted with Canadian Cancer Society staff, patient advisory groups, organizations that engage with underserved communities, cancer agencies and health organizations in Canada and internationally. These organizations were engaged for discussion about one or more communities that are underserved. The information collected through these interviews is included throughout the report.

The following list includes many of the organizations that participated in the stakeholder engagement component of the underserved communities project.

Access Alliance Multicultural Health and Community Services, African Cancer Support Group/Oladele Foundation, Alliance for Healthier Communities, British Columbia Cancer Agency, Canadian Association of Nurses in Oncology, Canadian Association of Social Workers, Canadian Hospice Palliative Care Association, Canadian Partnership Against Cancer, Canadian Organization for Rare Disorders, Carea Community Health Centre, COSTI Immigration Services, First Nations Health Authority, Healthcare Excellence Canada, Immigrant Services Association of Nova Scotia, McMaster University Gender, Health and Career-Friendly Workspaces, Métis Nation British Columbia, National Collaborating Centre for the Determinants of Health, OCASI - Ontario Council of Agencies Serving Immigrants, Public Health Ontario, Pauktuutit Inuit Women of Canada, Walnut Foundation, Women's College Hospital, Young Adult Cancer Canada

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Executive summary

The Canadian Cancer Society (CCS) is committed to improving and saving lives. We fund groundbreaking cancer research into all types of cancer. We offer trusted cancer information and support services to help people better manage life with cancer. We shape healthy public policy to help prevent cancer and improve the lives of people living with cancer and their caregivers. The need for cancer information and support is expected to grow as the number of people in Canada diagnosed with cancer continues to increase due to our growing and aging population.

In 2019, CCS started the underserved communities project, identifying communities that face barriers to accessing cancer information and support services. These barriers can result in poorer treatment, experience and outcomes. This project helps us understand the gaps, barriers and challenges faced by these communities. We outline community-specific opportunities and recommended tactics to address the issues.

CCS currently has identified 10 communities that are underserved with 25+ sub-categories. They are not the only communities underserved by CCS or the healthcare system. We have begun our work with these communities and will add more communities that are underserved over time.

- **2SLGBTQI+ communities**
- **adolescents and young adults with cancer**
- **advanced cancer**
- **communities that don't speak English or French**
- **Indigenous communities**
- **newcomers to Canada**
- **older adults**
- **racialized communities**
- **rare cancer**
- **rural and remote communities**

Both diversity and intersectionality are important considerations for this work. We recognize that people may identify with more than one community and bring those experiences with them.

A mixed-methods approach was used, with a combination of qualitative and quantitative data. The project included literature reviews, stakeholder interviews, and data and document reviews. The report describes the gaps, barriers and challenges of each of the 10 identified underserved communities and offers key considerations for engagement with the communities. The themes for gaps, barriers and challenges vary across communities, but there is also overlap among communities.

The following 5 actions are recommended by the underserved communities project for organizations that provide cancer information and support services. These recommendations will help to ensure that people within each community receive appropriate information, supports and resources. The 5 overall recommendations are to:

- 1. conduct dedicated training for staff**
- 2. evaluate internal capacity to conduct meaningful engagement with communities**
- 3. prepare for meaningful engagement with communities**
- 4. engage and co-design with communities to validate needs, opportunities and tactics**
- 5. co-create an evaluation framework to monitor the impact of information and supports**

The evidence gathered through the underserved communities project summarized in this report will guide engagement efforts and strategies to better help communities that are underserved with CCS's information and support services in a meaningful, evidence-informed way. This report and additional knowledge products are intended to share key learnings with other organizations that serve communities that are underserved through cancer information and support services.

Introduction

The need to advance health equity through cancer information and support

The Canadian Cancer Society currently offers cancer information, peer support and other practical supports for people with cancer and their family, friends and caregivers. Our [programs and services](#) help answer questions about cancer, managing life with cancer, finding community and connection, and building wellness and resilience. Many of the programs and resources are available in different languages.

The demand for these services is expected to grow as the number of people in Canada diagnosed with cancer continues to increase due to our growing and aging population. CCS has developed and will continue to develop strategies to engage with communities that face unique health disparities or barriers related to access and equity. This will be carried out using a person-centred approach.

Overview of the underserved communities project

In 2019, CCS started the underserved communities project. The purpose was to identify communities that face specific barriers to accessing cancer information and support services and to understand the gaps, barriers and challenges faced by these communities. The project then focused on developing evidence-informed roadmaps to outline opportunities and recommend tactics to address the barriers and challenges as well as identify partners to engage with in these communities. The final goal was to make recommendations to tailor CCS's current programs and resources to reduce barriers and ensure all people in Canada can access our cancer information and support services.

The evidence gathered through this project is the foundation for the ongoing work with underserved communities at CCS. The findings from this project allow CCS to begin engagement with the communities to explore the issues identified. To learn more about our additional and ongoing work with underserved communities, visit cancer.ca/HealthEquity.

Guiding principles

The following are guiding principles that encompass the beliefs and values held by CCS. These guiding principles were embedded in the work of the underserved communities project.

Health literate

Health literacy is the ability to find, understand, evaluate and use health information. A health literate organization makes it easier for people to navigate, understand and use information and services to take care of their health.

Person-centred

Person-centred information and support programs strive to adapt to a person's physical, emotional, spiritual and practical needs and recognize the person's role in managing their own health and that we are a partner for them. A person-centred organization prioritizes the needs of the people it serves, over all other considerations, to the greatest extent possible.

Culturally competent

Cultural competency strives to create an environment free of prejudice and discrimination. CCS strives to offer programs and services that are culturally sensitive, respectful, effective and safe for all clients.

Evidence-informed

Evidence-informed information and supports are based on the best available evidence, are comprehensive, relevant and accessible, and ensure people are objectively informed of potential benefits and limitations of health decisions.



Accessible

Accessibility ensures people are aware of and can easily find and use the information and support they need. Accessible information products and services enable everyone to participate without barriers.

Equitable

Equity recognizes that some communities and populations face unique barriers to accessing information and support services. An equitable organization works to reduce or eliminate such systemic barriers to access.

Effective

Information and support programs are measured and evaluated to ensure the desired outcomes are achieved.

Communities that are underserved

An underserved community in the context of health services is a population that is provided inadequate service and is systemically disadvantaged due to reasons including but not limited to race, age, language, geography, gender identity, sexual orientation and socioeconomic status. There are insufficient healthcare resources dedicated to the needs of underserved communities. The terms “underserved community” and “communities that are underserved” are used intentionally at CCS to reflect the responsibility we have in providing cancer information and support services to communities that experience health inequities. This term puts an emphasis on the surrounding systems that need to change instead of on the community.

CCS currently has identified 10 communities that are underserved with 25+ sub-categories. They are not the only communities underserved by CCS or the healthcare system. We have begun our work with these communities and will add more communities that are underserved over time.

- **2SLGBTQI+ communities**
- **adolescents and young adults with cancer**
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- **communities that don't speak English or French**
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- **older adults**
- **racialized communities**
- **rare cancer**
- **rural and remote communities**

Of the 10 communities selected, some face unique needs when it comes to their cancer diagnosis, their age or life stage, the language spoken or where they live. Many of these communities face systemic racism, marginalization, discrimination and stigma. This impacts their overall health, not just their cancer diagnosis and experience.

Diversity and intersectionality

Though 10 underserved communities have been defined for this work, it is important to recognize that diversity also exists within each community. Diversity is about the individual. It is about the variety of unique dimensions, qualities and characteristics we all possess. Not every person within an underserved community will have the same gaps, barriers and challenges with their cancer experience, but the evidence can help understand trends and what many people within an underserved community may face.

It is equally important to apply an intersectionality lens. Intersectionality is a term coined in 1989 by legal scholar Kimberlé Crenshaw to describe “a way of looking at the world that recognizes that people’s experiences are shaped by a combination of social factors, including their gender, racialization and age, among others. These experiences occur within and interact with connected systems and structures of power, such as sexism and racism.”* Intersectionality is a lens through which we can observe the way various forms of inequality operate together and make one another worse.

* Knowledge Translation Program. Intersectionality and KT. <https://knowledgetranslation.net/portfolios/intersectionality-and-kt/>. Published 2017. Accessed February 14, 2023.

In this report and through the work happening at CCS, we defined underserved communities so that we can identify supports for needs in each community. However, we recognize that people may identify with more than one community and bring those experiences with them.

Availability of data

Limited available data can make it difficult to determine cancer patterns and health trends in communities that are underserved. It can also make it hard to create initiatives to reduce disparities in accessing cancer care. Data that is collected is not always reported back to the communities or researchers who may be able to use it. Where available, population and cancer statistics are included in this report. The real extent of the disproportionate effects of cancer on underserved communities in Canada isn't yet known, due to the lack of data collected.

Data collection must be improved to address existing gaps and help reduce health inequities among communities that are underserved across the cancer control continuum. Access to timely data that is complete, representative and disaggregated will help inform decisions to plan, prepare for and fund cancer care in Canada. This includes but isn't limited to race-based data, gender identity and sexual orientation. Any Indigenous-specific data must be collected using [First Nations Principles of OCAP®](#) (ownership, control, access and possession), [Inuit research principles](#) or [Métis research protocol OCAS principles](#) (ownership, control, access and stewardship).

Methods

Identifying underserved communities

Underserved communities featured in this report were identified in collaboration between CCS and the Canadian Partnership Against Cancer over the course of the project. We recognize that these are not the only communities underserved by CCS or the healthcare system.

Methodology

A mixed-methods approach using a combination of qualitative and quantitative data was used in this project. The project included literature reviews, stakeholder interviews and data and document reviews. The literature reviews used databases such as PubMed, Scopus and Web of Science. For literature around cancer information and support challenges for people who do not speak French where care is delivered primarily in French, scientific literature was reviewed in both English and French databases. Key informant interviews were conducted with CCS staff, patient advisory groups, organizations that engage with underserved communities, cancer agencies, and health organizations in Canada and internationally. Lastly, data and document reviews were conducted of both internal and external documents, including various frameworks, performance reports and survey report outcomes. This work was completed between 2019 and 2022. Additional details about search terms and search approaches are available [upon request](#).

The findings from this project are shared in the next sections of this report, which cover the 10 identified underserved communities.

Lastly, although the gaps, barriers and challenges are highlighted along with the opportunities and recommended tactics to improve supports specifically for each underserved community, it is important to note that addressing an opportunity to improve supports for one community will also provide better information and support for other communities.

Disclaimer

Most organizations that provide information, peer and practical support don't provide any medical or clinical programs, but all could have a role in providing information, developing or expanding non-clinical programs and referring to clinical programs. The recommended tactics throughout each of the underserved community chapters reflect that role. Some of the recommended tactics may be connected to existing CCS offerings, but may also include tactics that are beyond our scope to inform the work of the broader cancer information and support community. We recognize that many of these recommended tactics may or may not exist locally, and we acknowledge that where they do exist, they may not be implemented everywhere or consistently. An assessment of recommended tactics was not performed for this report. They reflect what we heard from organizations and saw in the published research and reports.

Reflections

CCS acknowledges that we did not engage directly with communities that are underserved at this stage of our work. This was intentional. Our primary goal was to understand the issues through the evidence and through stakeholder engagement with organizations that serve these communities first. We are committed to engaging with underserved communities and incorporating valuable perspectives of people with lived experience in our ongoing work. In fact, CCS has started several projects to better address the needs of people who are underserved by CCS and the cancer system (see cancer.ca/HealthEquity). As we do our work in each of these projects we will be focused on learning and improving our own practices. Although all our practices are not yet where we want them to be, our ultimate goal is that at each stage of the projects – from design to implementation and evaluation – we will engage people from the communities as partners in our work and encourage other organizations to do the same.

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Knowledge Translation Program. Intersectionality and KT. <https://knowledgetranslation.net/portfolios/intersectionality-and-kt/>. Published 2017. Accessed February 14, 2023.



2SLGBTQI+

2SLGBTQI+ refers to people who identify as Two-Spirit, lesbian, gay, bisexual, trans, queer or questioning, and intersex.

The “+” indicates other identities and experiences that fall outside the dominant heterosexual and cisgender (non-trans) identities (e.g. asexual, demisexual, pansexual).

Please see the appendix at the end of this 2SLGBTQI+ section for definitions of the subcommunities.

Introduction

There are about 1 million people in Canada who are gender and sexually diverse (2SLGBTQI+), making up about 4% of the total population aged 15 and older in 2018. There is limited data available on cancer statistics for 2SLGBTQI+ communities. The physical health of 2SLGBTQI+ Canadians is understudied, and health problems are not as well documented among some 2SLGBTQI+ communities as others. However, international research suggests that the rates of people who get cancer differ among 2SLGBTQI+ communities compared to the general population.

2SLGBTQI+ communities experience inequities in health and cancer care due to the stigmatization and discrimination they face within the health system and broader society that create significant barriers to access, experience and ultimately outcomes. In Canadian society, practices and conventions are largely based on the assumption that all people are heterosexual and cisgender. As a result, health systems often adhere to cis- and heteronormative practices that do not address the unique needs of 2SLGBTQI+ people. Many members of 2SLGBTQI+ communities have endured negative healthcare experiences as a result of unwelcoming, discriminatory, poorly trained or uninformed healthcare providers.

Gaps, barriers and challenges in care

Disclosure

Fear of discrimination is a barrier to accessing healthcare services for 2SLGBTQI+ communities. People with cancer may have had negative experiences in the past disclosing their sexual orientation to their healthcare provider, which can lead to hesitancy to tell future healthcare providers. A Canadian study found that lesbian and bisexual women may be reluctant to disclose their sexual orientation if asked by a healthcare provider, due to fears of receiving diminished care or encountering hostility. Being distrustful of the healthcare system and providers as a result of negative experiences may lead to a delay or avoidance in routine care and cancer screening, which can lead to later-stage diagnoses and an increased likelihood of death.

Some people with cancer may feel that disclosing their sexual orientation is irrelevant or that healthcare providers should be initiating the conversation about their sexual orientation. Other people with cancer said that being open about their sexual orientation with their healthcare providers benefits their mental and physical health. Being open about the correct pronouns, names or partner status can increase comfort with the medical team, which can lead to better health outcomes.

Without disclosure, people with cancer may feel uncomfortable including their partner or chosen family in their cancer care, which can lead to poorer outcomes. When seeking cancer treatment, disclosure of sexual orientation, gender identity and transition, within a safe space, can be important to ensure quality of care. For example, discussing an individual's use of hormone therapies and the details of their gender transition can allow the healthcare providers to offer the most informed treatment choices.

Homophobia and heteronormativity

Many people who are 2SLGBTQI+ have been denied healthcare due to homophobia or transphobia. People are often assumed to be in heterosexual relationships, and some health professionals have excluded or denied a same-gender partner from being involved during cancer care. Stereotypes or assumptions about 2SLGBTQI+ communities by healthcare providers can impact how comfortable or safe people feel when accessing care. 2SLGBTQI+ people have described feeling highly sensitive or having a heightened awareness during clinical appointments as they determine whether their healthcare provider knows how to respond to sexual or gender diversity. A Canadian study found that many youth experienced homophobic healthcare providers and chose to seek health information privately. Cancer survivorship or recovery can also include heteronormative assumptions that can disaffirm gender identity. For example, not all people with cancer will want breast reconstruction following breast cancer surgery.

Inclusion and feeling welcome

People with cancer who are 2SLGBTQI+ need a welcoming physical and administrative environment and positive relationships with their healthcare providers. A safe and supportive environment is needed and important when undergoing treatment for both the individual with cancer and their caregiver.

Young 2SLGBTQI+ people value positive relationships and belonging in healthcare settings and may opt out of clinical relations that do not meet their needs. This includes avoiding the awkwardness of engaging with healthcare providers who don't know how to create inclusive clinical environments.

Healthcare provider competency

Many healthcare providers do not have sufficient training to understand the unique healthcare needs and experiences of the 2SLGBTQI+ community. The lack of support for people who are 2SLGBTQI+, such as lesbian and bisexual women, may be due to a poor overall understanding of sexual identities and relationships. Studies found that routine clinical questions about whether an individual is sexually active or using birth control can be difficult for people who are 2SLGBTQI+, especially if they prefer not to disclose their sexual orientation. Healthcare providers should also be aware that certain types of cancer screening may not be gender affirming for transgender people, as this can result in a psychosocially and emotionally painful experience. However, receiving care from competent and sensitive healthcare providers improves these experiences and increases the likelihood of seeking routine care. Healthcare providers need training to understand how their biases and assumptions show up in their delivery of care and education on how to respond to the needs of 2SLGBTQI+ people with cancer and provide appropriate care.

Trauma-informed care

People who identify as 2SLGBTQI+ are more likely to experience stress, violence, discrimination and trauma in their lifetime. Given these experiences, physical and emotional safety are key when providing care to 2SLGBTQI+ individuals. Safety in trauma-informed care involves allowing 2SLGBTQI+ people to maintain a sense of choice, dignity and personal control in their care. Healthcare providers should create a space that is affirming and non-judgmental and minimizes power imbalances. There is an urgent need for anti-oppressive and intersectional trauma-informed care interventions to avoid retraumatization in 2SLGBTQI+ people.

Social support

Social support is very important when coping with a cancer diagnosis, but for many people who are 2SLGBTQI+, biological family members may not be a primary source of support. For many, partners, friends or “chosen family” members may offer support during a cancer diagnosis. People who don’t have social support and are struggling with their identities may have additional unmet needs and can often experience frustration and isolation through their cancer experience.

Studies found that gay and bisexual men with prostate cancer receive variable but often low social support from their social network. After diagnosis, many men reported seeking information and emotional support from prostate cancer support groups, but many wanted support groups specifically for gay and bisexual men with prostate cancer.

Recognition of 2SLGBTQI+ communities as distinct groups

There is a need to identify and recognize 2SLGBTQI+ communities as distinct groups to optimize healthcare provision and quality. Without this identification, people may receive medically wrong or harmful information. Among these communities, a need to acknowledge bisexual people as a distinct subcommunity was identified. This community often faces stigma and double discrimination from both heterosexual and 2SLGBTQI+ people.

2SLGBTQI+ specific care

There are limited health resources that reflect 2SLGBTQI+ communities. Often, many available supports for 2SLGBTQI+ communities are lumped together and don’t use language that is inclusive and appropriate to these communities. Many 2SLGBTQI+ youth opt to teach themselves how to find health information online related to their sexual orientation. A lack of specialized care can lead to poorer mental and physical health for members of 2SLGBTQI+ communities.

Caregivers

2SLGBTQI+ people are more likely to provide or receive care by someone outside of a traditional family structure, such as a friend or someone who is part of their chosen family. Additionally, partners of 2SLGBTQI+ people also have unmet needs and supports when caring for their partner during cancer treatment. Heteronormative and cisnormative assumptions in healthcare settings hinder access to supports needed for caregivers. One study found that caregivers in same-gender relationships who are given support and acceptance of their relationship feel more comfortable being intimate and providing emotional support to their partner with cancer.

Financial challenges

2SLGBTQI+ people with cancer face financial stress due to possible loss of employment, medical absence, passing up employment or advancement opportunities or possible employment discrimination.

Key considerations for engagement

- 2SLGBTQI+ people want to be seen and valued for who they are and not have their sexual orientation or gender identity erased.
- 2SLGBTQI+ people want resources and supports that reflect their identities and experiences.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information for people who are 2SLGBTQI+ using multiple channels.	<ul style="list-style-type: none"> • Ensure outreach strategy includes multiple channels such as online tools. • Increase information on cancer survivor concerns for people who are 2SLGBTQI+ through collaboration with cancer survivors who are 2SLGBTQI+ to ensure information is presented in accessible formats. • Ensure language used in content is relevant and evolves as needed. • Partner with organizations to identify 2SLGBTQI+ positive supports. • Use digital storytelling on video platforms by people from 2SLGBTQI+ communities speaking about their experience. • Increase availability of and access to tailored resources that reflect 2SLGBTQI+ communities and 2SLGBTQI+ specific health information. • Increase health information tailored for 2SLGBTQI+ youth. • Increase information for transgender people with cancer who may stop hormone treatment to treat cancer.

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Peer	Increase availability and accessibility of peer supports for people who are 2SLGBTQI+ that foster a welcoming and inclusive environment.	<ul style="list-style-type: none"> • Ensure peer matching includes 2SLGBTQI+ people. • Partner with support programs to provide offerings that are 2SLGBTQI+ peer led. • Create a support framework for 2SLGBTQI+ people that existing programs can leverage for their programming. • Create training workshops to develop additional supports with 2SLGBTQI+ communities. • Increase specific cancer support groups for subcommunities within 2SLGBTQI+ communities. • Increase awareness and access to psychosocial supports for transgender people with cancer who may stop hormone treatment to treat cancer.
Practical	Increase availability and accessibility of practical supports for people who are 2SLGBTQI+.	<ul style="list-style-type: none"> • Ensure healthcare providers receive 2SLGBTQI+ clinical and cultural competency training. • Increase training to use appropriate language when caring for people with cancer (e.g. appropriate pronouns).

Appendix

The Canadian Cancer Society uses the acronym 2SLGBTQI+ but acknowledges that this is just one of many acronyms used and people use many words to describe sexual orientation and gender identity. The definitions below are not standardized and may be used differently by different people in different regions, countries and cultures. The “+” indicates other identities and experiences that fall outside the dominant heterosexual and cisgender (non-trans) identities (e.g. asexual, demisexual, pansexual). Though we’ve chosen this acronym and used it broadly, we also recognize and support where a different acronym or language may be more appropriate to a certain audience.

Definitions of 2SLGBTQI+ subcommunities

- **Two-Spirit** (an English term used in some Indigenous communities across North America encompassing a wide variety of Indigenous concepts of gender and sexual diversity. Two-Spirit people often serve integral and important roles in their communities, such as leaders and healers. There are many understandings of the term Two-Spirit – and this term does not resonate for everyone. Instead, people may identify with a term specific to their nation, as many Indigenous languages have words for gender and sexual diversity traditionally found in their communities. Two-Spirit is a cultural term reserved for those who identify as Indigenous.)
- **lesbian** (a woman who is attracted to women)
- **gay** (a person who is attracted to people of the same gender. The word can refer to men or women, although some women prefer “lesbian.”)
- **bisexual** (a person who is attracted to people of more than one gender)
- **trans** (an umbrella term referring to people whose gender identities differ from the sex they were assigned at birth. “Trans” can mean transcending beyond, existing between, or crossing over the gender spectrum. It includes, but is not limited to, people who identify as transgender, transsexual, non-binary or gender non-conforming [gender variant or genderqueer].)
- **queer** (an umbrella term used and reclaimed by some whose sexual orientations or gender identities fall outside the dominant heterosexual and cisgender identities)
- **questioning** (a period where a person explores their own sexual or gender identity, reflecting on such things as upbringing, expectations from others and how they see themselves. The person may not be certain if they are gay, lesbian, bisexual or trans and may be trying to figure out how to identify themselves.)
- **intersex** (an umbrella term referring to people born with sex characteristics [external or internal sex organs, chromosomes or sex hormones] that fall outside of the strict binary of male or female. Being intersex is a naturally occurring variation in people. Typically, intersex people are assigned one sex, male or female, at birth. Just like everyone else, people who are intersex have a range of gender identities.)

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Adolescents and young adults with cancer

Adolescents and young adults with cancer (AYAs) refers to people who are aged 15 to 39 years when diagnosed with cancer. In some cases, younger or older people are included.

Subcommunities

- **Early adulthood (15 to 19 years)**
- **Young adulthood (20 to 24 years)**
- **Late young adulthood (25 to 39 years)**

Introduction

As of 2021, Canada was home to about 12.5 million adolescents and young adults between the ages of 15 and 39, making up 32.7% of the total population. About 7,000 Canadians aged 15 to 39 were diagnosed with cancer in 2018. Adolescents and young adults who are diagnosed with cancer (AYAs) have unique developmental, psychosocial and self-management needs. Depending on their age and which subcommunity they belong to (early adulthood, young adulthood or late young adulthood), the needs can vary or be more prominent. Further, for AYAs, a cancer diagnosis can disrupt many milestone life events, which can further intensify their need for support.

Gaps, barriers and challenges in care

Career and education

A cancer diagnosis can interrupt many things in your life. For AYAs who are between the ages of 15 and 19, a diagnosis can interrupt high school. For AYAs between the ages of 20 and 39, a diagnosis can interrupt their post-secondary education or their career. Many AYA cancer survivors often started employment later with more absent workdays than the general population. Gaps in work experience can make it hard to find a job, and cancer treatments, including surgery, chemotherapy and radiation, were associated with an increased risk of self-reported mental impairment in work tasks. Interruptions and treatment can limit a person's academic or career progress and can create barriers to establishing relationships with employers or teachers. Moreover, educational institutions and workplaces may not have knowledge, awareness, policies or procedures in place to support the needs of AYAs.

Self-management

AYAs may not have developed skills such as communication, coping and other tools for self-management. They may also not be aware of their own needs or what supports to ask for. Further, they may reject support to maintain their independence.

Continuity of care

AYAs may not have access to a primary care provider to ensure continued follow-up, routine screening and other important components of care.

Physical challenges

AYAs have reported the need for help managing the side effects of treatment. Challenges reported by young adult cancer survivors include sleep disturbances, fatigue, weight gain, and motor and cognitive impairments. For some AYAs, organs may still be developing and are very sensitive to the damaging effects of chemotherapy and radiation treatment, which can contribute to late or lasting side effects. Impaired body image has often been shared as a negative impact among AYA cancer survivors, as they face changes in their appearance such as weight gain or loss, hair loss and scars.

Being diagnosed with cancer at an early age increases the risk of new cancers and other chronic health conditions such as diabetes and cardiovascular disease. It can also negatively impact mental health, fertility and intimacy. Certain types of treatment have been associated with long-term complications in AYA cancer survivors.

Information

Overall, there is limited age-specific information on AYAs. This includes but is not limited to information on fertility, diet and nutrition, exercise, palliative care and the potential for late effects related to cancer treatment.

AYAs may also experience challenges related to health literacy. AYAs have reported the need for repetition in information as it can be difficult to retain. AYAs have requested that information related to exercise be available in various formats, including brochures and online, and would like it to include recommendations for fitness or exercise programs. AYAs also need assistance when navigating appropriate resources for cancer and treatment, as exposure to some resources may cause distress.

Psychosocial needs

Adolescence and young adulthood is a period of important development milestones, which include developing values and personal identity, forming strong personal relationships and gaining financial independence. AYAs may not have enough life experience to develop adequate coping skills to manage the impacts that result from a cancer experience. Therefore, their development status and psychosocial needs are unique.

AYAs have reported a number of emotional needs and experiences such as fears that the cancer will come back (recur) and early death. These feelings can last until long after treatment has finished. They often report feelings of disconnection from peers, which can lead to social isolation and negative impacts to their self-esteem and self-identity. AYAs in early and young adulthood experience an increase in parental overprotectiveness and forced dependence, which may lead to feeling a loss of control, anxiety and depression. In different stages of their life, AYAs have increased challenges with close relationships such as marital stress, increased difficulties in raising a child and grief related to interrupted future plans including sexual health, romantic relationships, starting a family and education or career progress.

Traditional healthcare and treatment facilities are not designed for AYAs' specific psychosocial needs, and specialized AYA clinics are often scarce.

Trauma-informed care

For AYAs, the diagnosis of cancer at a critical stage in their personal and social development may cause additional distress and may result in a diagnosis of post-traumatic stress, anxiety or depressive disorders. There are several factors such as being female, having less social support and experiencing self-image and identity issues that are associated with higher distress levels in AYAs. Additionally, this distress is higher in AYAs aged 15 to 19 years, meaning that it must be a priority to provide more accessible and age-appropriate psychological support using a trauma-informed approach.

Financial challenges

AYAs are more likely to be financially dependent on their caregivers. AYAs can also face higher unemployment rates, which can contribute to a greater financial burden due to out-of-pocket costs for medications, transportation and possible childcare-related expenses. AYAs have accumulated fewer assets than people their age who don't have cancer, and AYA cancer survivors often report borrowing more than \$10,000. AYAs who were diagnosed at a younger age and had extensive chemotherapy treatment were found to be at higher risk for financial hardship.

Fertility

A common fear reported among AYAs is the fear of infertility. The long-term effects that cancer treatment may have on fertility are not always discussed with the healthcare team, and there is limited information available about resources and referrals related to fertility. Fertility preservation for AYAs can be difficult due to cost, lack of time or limited counselling. Some people have expressed concerns about delaying treatment to pursue fertility preservation.

Palliative care

There is limited information available on palliative care services for AYAs. More research is needed to understand the unique palliative care needs for the AYA population. Further, discussions to inform people of the benefits of palliative care and identify the best methods to promote AYA referrals to palliative care are needed.

Key considerations for engagement

- AYAs want to be able to find age-specific information, resources and practical supports that reflect their unique experiences.
- AYAs want to connect with peers facing similar experiences.
- AYAs want to see investments in cancer research that studies AYAs.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information for AYAs and their caregivers using multiple channels.	<ul style="list-style-type: none"> • Increase awareness about AYAs. • Develop or improve access to information on the late effects from cancer and its treatment. • Use plain language on websites and other cancer information materials. • Develop tailored materials for AYAs to include specific challenges (e.g. back-to-work information). • Engage AYA communities and their caregivers about career and financial planning, fertility and sexual health. • Partner with AYA organizations for events such as financial planning information sessions. • Ensure that oncofertility services for AYAs are promoted. • Engage with AYAs to expand digital storytelling to include the AYA experience. • Assist with navigation of appropriate resources.
Peer	Increase availability and accessibility of peer supports for AYAs and their caregivers through multiple channels.	<ul style="list-style-type: none"> • Ensure peer matching includes AYAs across varying stages of their life. • Partner and collaborate with local organizations that have strong relationships with AYAs. • Develop support groups or programs that teach AYAs emotional coping strategies and stress-management programs. • Ensure online cancer forums are mobile responsive and have AYA moderators. • Design physical activity programs to increase self-management and build peer support networks. • Develop group activities such as camps to help AYAs develop friendships with peers.

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Practical	Increase availability and accessibility of practical supports for AYAs and their caregivers.	<ul style="list-style-type: none"> • Collaborate with organizations to develop or expand and promote practical support needs such as financial planning, physical therapy, mental health services, pain management, fertility preservation services and career support. • Increase referrals to AYA organizations with practical supports. • Develop or expand transportation services to support AYAs and caregivers with financial challenges. • Increase financial supports for AYAs. • Increase awareness of counselling services for AYAs. • Increase referrals to specialized palliative care services for AYAs. • Increase referrals to therapy or counselling to address mental health challenges related to an individual's cancer experience. • Increase awareness of self-care strategies such as exercise, meditation, journalling, art and music. • Increase or raise awareness of supports related to establishing or resuming careers. • Increase or raise awareness of the need for more research for AYA-tailored interventions.

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Advanced cancer

Advanced cancer is a cancer that is unlikely to be cured, and the focus of care changes in physical, emotional and practical ways. Advanced cancer is also known as metastatic, terminal, end-stage or stage 4 cancer. For some people, the cancer may already be advanced when it is diagnosed. For others, the cancer may not become advanced until years after it was first diagnosed.

Introduction

In Canada, cancer stage is not consistently recorded for all cancer types in cancer surveillance data. And when it is recorded, it is only at the time of diagnosis. This means that surveillance data won't necessarily include advanced stages that some cancers progress toward after diagnosis. Therefore, it is hard to determine the number of people in Canada living with advanced cancer. Adjusting to an advanced cancer diagnosis can take time for people with cancer and their families. While advanced cancer likely cannot be cured, there are still things that can be done to help people with cancer and their families have a good quality of life for as long as possible, such as palliative care. In navigating an advanced cancer diagnosis, people with advanced cancer, their caregivers and their families may have a range of unmet physical, psychosocial, spiritual and informational needs. People with advanced cancer often face unique challenges and barriers to receiving appropriate emotional and practical support.

Gaps, barriers and challenges in care

Physical and emotional symptom management

Some of the top unmet physical and emotional needs for people living with advanced cancer are managing fatigue, anxiety and fear. Fatigue was named as a key source of distress for people with advanced cancer, causing a large disruption to their life. Symptoms of distress and anxiety were consistently reported across many studies, resulting in a low quality of life. Many people with advanced cancer feel anxious about the unpredictability of the disease and their future, with the highest anxiety levels felt at the time of diagnosis of advanced disease. Many people also reported fear due to unknown changes that could happen over time.

Information

People with advanced cancer expressed interest in having as much information as possible about their diagnosis, treatment and treatment-related side effects, along with the likely outcome of their disease. Studies found that people with advanced cancer who received palliative radiotherapy wanted to know more information about their disease and treatment and did not feel they had enough information to understand the benefits and risks. Overall, studies found there are gaps in information related to palliative care and advanced care planning at diagnosis.

Trauma-informed care

People with advanced cancer live knowing that their illness likely cannot be cured. In response to their diagnosis, they may experience symptoms consistent with post-traumatic stress disorder (PTSD). People with advanced cancer have reported that their cancer diagnosis was the most traumatic event of their lives. There is a lack of evidence of trauma-informed care in the context of cancer, which makes it hard for healthcare providers to understand the value of trauma-informed care for people living with advanced cancer.

Peer support

People with advanced cancer are frequent users of peer support programs, but these programs are not always designed to meet their needs. There are limited supports available or accessible to people with advanced cancer, which can lead to feelings of isolation and disconnection from others. The 3 main forms of peer support are one-to-one support, group support and online support.

Palliative care and end-of-life support

Palliative care aims to prevent and relieve discomfort and improve quality of life at all stages of cancer. This can be of great benefit to people with advanced cancer and their families as palliative care addresses physical, psychosocial and spiritual suffering. Studies found that many people with advanced cancer are not aware of palliative care and end-of-life resources in their region, and that many of the resources that do exist may not be aligned with the needs of people with advanced cancer and their families.

Caregivers

Caring for someone with advanced cancer can feel overwhelming and challenging at times. Caregivers themselves may feel various emotions such as denial, anger, fear, sadness and grief. In one study, 30% of caregivers indicated that managing their emotions was the most challenging aspect of being a caregiver. This is important as the relationship between a caregiver and a person with advanced cancer is bi-directional, and thus if a caregiver is experiencing distress, it can impact the physical and mental health of the person with cancer.

Palliative care can benefit caregivers of people with advanced cancer as support for both practical and emotional caregiving needs. A palliative care team can include disease-specific specialists, social workers, psychologists and personal support workers who can help take some of the work away from caregivers. Additionally, grief and bereavement support can be provided if needed.

Financial challenges

People with advanced cancer often worry about managing finances when they are unable to work for an extended period. They are concerned about the well-being of their family, financially, physically and emotionally. Financial stress is a higher concern among younger people, especially those with children under the age of 18. It can also be hard to pay for all or part of treatment or products and services that are not covered by provincial or territorial health insurance plans. Lodging and transportation issues can also be financial challenges and were associated with anxiety, depression and poor quality of life.

Nutritional support

Evidence indicates that people with advanced cancer have a lack of knowledge about cancer cachexia (unintentional weight loss) and have had difficulties with attempting to increase body weight. Lack of appetite and loss of body weight can also be a source of distress for families. People with advanced cancer often ate because they felt pressured to eat, and not because they wanted to eat. Some people with advanced cancer want some degree of control and choice over the foods and drinks they consume, which may lead to conflicts with their family or caregivers.

Spiritual support

Research found that religion and spirituality can be linked to health and healthcare outcomes. For example, negative outcomes were found more often during end-of-life care when a person was more religious. A study found that people with advanced cancer receiving high levels of spiritual support from religious communities were less likely to receive hospice care and were more likely to receive aggressive interventions at end-of-life and die in an ICU. These interventions include care in the ICU, resuscitation or ventilation. The study also found that racialized people who felt a strong connection to a spiritual community were at the greatest risk of receiving aggressive interventions at the end of life. A person's spiritual values should be considered a component of discussing and addressing end-of-life support.

Daily home help

Although there is a strong desire to continue to engage in daily activities at home, the type or layout of the home can cause various challenges for people with advanced cancer. People with advanced cancer spend significant time at home engaging in self-care and sedentary leisure. However, they report problems around performing household activities due to extra time needed, effort, safety risk, mobility or needing assistance. Heavy household activities were reported as the most problematic, but many participants in one study prioritized wanting support to assist with more active leisure and social activities.

Key considerations for engagement

- People with advanced cancer want to have resources appropriate to their situation, including both emotional and practical supports.
- It is important to ensure that the purpose of engagement is well-defined, the timing and methods of engagement are flexible, and the needs of people with advanced cancer are addressed throughout the process.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information for people with advanced cancer and their caregivers using multiple channels.	<ul style="list-style-type: none"> • Expand awareness on commonly reported symptoms. • Ensure information and supports include coping strategies related to chronic disease management. • Use digital storytelling to deliver therapeutic messaging for people with advanced cancer. • Develop advanced cancer guides to provide information on navigating illness, finding support and end-of-life decision-making. • Ensure palliative care information is current with the evolving model of palliative care. • Ensure palliative care resources are more accessible to people. • Leverage evidence-informed content from other organizations working alongside people with advanced cancer.
Peer	Increase availability and accessibility of peer supports for people with advanced cancer and their caregivers through multiple channels.	<ul style="list-style-type: none"> • Create or leverage existing support groups to connect people with advanced cancer to resources. • Increase peer matching programs to include advanced cancer. • Create an advanced cancer support group framework that incorporates lessons learned to enhance peer support offerings. • Offer online support groups to help someone newly diagnosed with cancer navigate their illness and for people who are not comfortable talking to someone face-to-face about their illness.
Practical	Increase availability and accessibility of practical supports for people with advanced cancer and their caregivers.	<ul style="list-style-type: none"> • Ensure that practical support service providers receive the proper training to listen and refer people to supports related to their common concerns (e.g. anxiety, fatigue, financial stress). • Increase awareness and access to programs to provide financial relief to people with advanced cancer. • Ensure awareness and access to technical aids to assist people with advanced cancer to perform activities of daily living. • Ensure awareness and access to palliative rehabilitation services. • Increase awareness of the role of spiritual support in care.

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Communities that don't speak English or French

Communities that don't speak English or French refers to people living in Canada who are not able to communicate in either official language that might be used to deliver their care. These people are from numerous ethnicities and cultural backgrounds.

Introduction

English and French remain the most spoken languages in Canada. However, 4.6 million Canadians predominantly speak a language other than English or French at home most of the time, and about 580,000 Canadians (1.6% of the population that speaks at least one non-official language) do not speak either English or French. There are more than 324 languages being spoken in Canada. People with cancer who are not able to communicate in either of Canada's official languages or 1 of the 2 languages may experience difficulties throughout their cancer experience. There is limited data available on cancer statistics for people who don't speak English or French or people who speak neither language.

Healthcare providers may speak either English or French as their primary language depending on where they practise in Canada. This may add barriers to communication. Difficulty understanding medical language can result in poorer participation and outcomes in the healthcare system. In the cancer context not being able to communicate in English or French, or having low proficiency in these languages, can be a significant barrier to accessing health services such as cancer screening and treatment. There are many unmet needs for this community including the need for quality online cancer information, culturally tailored programs, resources available in multiple languages and increased access to credible sources.

There is a lack of scientific literature around cancer information and support challenges for people with cancer who do not speak French where care is delivered primarily in French. Some information on communities that don't speak French is included in this section. Many gaps, barriers and challenges faced by communities that do not speak French may be similar to those faced by people who do not speak English.

Gaps, barriers and challenges in care

Language barriers

The most commonly faced issue by those who do not speak English or French is language barriers. If a person cannot receive services in their first language, it can lead to misunderstandings of information received, either directly through a healthcare provider or from other supports and services. While the use of interpreters for translation can support people who do not speak English or French, the services are not always culturally appropriate, and they may not take privacy concerns into account.

Additionally, the use of family members or friends to translate is helpful but not ideal as they may not be trained in medical terminology and may not translate all information if topics are of a sensitive nature. Furthermore, children are often the providers of informal interpreting between the healthcare provider and the person who is seeking care, and they are expected to be the mediators between the family and their care providers. However, children may not have enough proficiency in either language and not enough emotional maturity to deal with sensitive healthcare topics. This can leave children with a mental burden and inappropriate emotional concerns. It must be a priority to address the burden that children and youth experience by being interpreters for their families.

Lastly, not being able to speak the language used in the healthcare system or understand the available information and supports can lead to feelings of isolation in the system.

Healthcare providers

Cultural competency is essential. Lack of cultural competency in healthcare providers and underrepresentation of ethnicity in healthcare professions may impact seeking care for people who do not speak English or French.

Communication channels

Many people who don't speak English or French are unable to use general communications and need more tailored approaches. In addition, it's important to choose the right communication channel.

Access to available services

Many newcomers to Canada do not speak English or French, and only a small proportion of those will access the resources available to them. Many of these people will only learn of available services and supports through word-of-mouth, when they actively seek them out or by chance at community events. For some people, the term "cancer" itself may be taboo and prevent them from seeking services.

There is also a lack of community-specific services. Cultural differences may limit the use of services and information, and many different factors, such as religion or gender roles, can also influence uptake. Most of the services that are available do not address or recognize the role of traditional medicine or the practice of a given culture. Lastly, many people who do not speak English or French may face discrimination in the healthcare system, often attributed to misunderstandings and incorrect assumptions.

Financial challenges

People who do not speak English or French may face financial difficulties and lower income, which may reduce their access to certain services and supports.

Caregivers

For caregivers, language barriers can hinder the ability to care for a person with cancer. Studies found that immigrant parent caregiving roles were challenging when they were unable to learn the complex medical terminology or understand the treatment process. Language barriers can impact awareness of service options, health literacy and self-esteem, causing high caregiver distress.

Trauma-informed care

Not having English or French as a first language may prevent people from communicating trauma. The difference in language and cultural norms can cause people who are not fluent in English or French to be hesitant in communicating their trauma to their healthcare providers. There is limited information regarding trauma-informed care to people who don't speak English or French. However, it is known that when communicating, language plays a crucial role for receiving effective care, starting with screening to identify trauma and how language may influence the results.

Impact of travel

Language barriers can result in difficulties navigating public transportation systems.

Rural environment

Challenges associated with not speaking either English or French are heightened in rural environments due to the limited availability of services or access to services, and a lack of community supports such as religious institutions.

Key considerations for engagement

- Language barriers can result in a misunderstanding of information and services and lead to people feeling isolated in the system.
- Tailored communication approaches that reach the community directly are the most successful.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability, accessibility and cultural relevancy of information using multiple channels and delivery through multiple languages.	<ul style="list-style-type: none"> • Partner with community health centres, faith organizations, local immigrant partnerships and others to reach all members of a community. • Collaborate with organizations to identify community leaders. • Deliver information through multiple communication channels. • Ensure outreach strategy includes engagement through non-print (including online and social media) and in person (including community events and community centres). • Ensure content is translated and adapted for various languages. • Ensure content reinforces cultural norms and values specific to cultural identities. • Materials should be presented in plain language, be culturally appropriate and include graphics where possible. • Use digital storytelling on video platforms for people impacted by cancer to tell stories about their experience within a particular community.
Peer	Increase availability and accessibility of peer supports through multiple channels for people who don't speak English or French.	<ul style="list-style-type: none"> • Ensure peer matching includes people from communities who speak languages other than English or French. • Increase the number of peers and mentor volunteers with various language capabilities. • Increase knowledge of peer support program to relevant community members. • Ensure supports reinforce cultural norms and values specific to cultural identities. • Use community centres dedicated to specific communities as a hub for peer support.
Practical	Increase availability and accessibility of practical supports for people who don't speak English or French.	<ul style="list-style-type: none"> • Recruit practical support service providers from various communities that can speak languages other than English or French. • Ensure that practical support service providers receive the required training to listen and refer people to supports related to their common concerns. • Provide interpretation services. • Increase awareness of financial resources. • Ensure information about financial and practical supports is available online in various languages.

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Indigenous communities

Indigenous peoples are descendants of the first inhabitants of what is now Canada. It is a collective noun for First Nations people, Inuit and Métis.

First Nations people are descendants of the original inhabitants of Canada who lived here for many thousands of years before explorers arrived from Europe. First Nations people identify themselves by the nation to which they belong.

Inuit are the original inhabitants of the northern regions of Canada. The word *Inuit* means “the people” in the most commonly used Inuit language of Inuktitut.

Métis includes a person who self-identifies as Métis, is distinct from other Indigenous peoples, is of historic Métis Nation ancestry and is accepted by the Métis Nation.

Urban Indigenous people refers primarily to First Nations people, Inuit and Métis currently residing in urban areas.

Introduction

As of 2021, the population of Indigenous peoples in Canada was about 1.8 million, equivalent to 5% of the Canadian population, and it is expected to reach between 2.5 million and 3.2 million over the next 20 years. First Nations, Inuit and Métis populations have been significantly impacted by colonial structures and processes, which continue to result in health inequities and disparities. There is limited data available on cancer statistics for Indigenous communities. Mortality rates for certain cancers are higher in some Indigenous communities compared to the general population living in Canada. This is associated with the unmet needs of continuity of care, culturally appropriate treatment, education and support services.

Indigenous peoples

Gaps, barriers and challenges in care

Colonialism, racism and mistrust in the system

Colonial structures and processes have created inequities, resulting in multi-generational health disparities.

Indigenous peoples often face racism or discrimination when receiving healthcare services. This can happen through healthcare providers acting on stereotypes and prejudice and making assumptions about how much information a person has or what supports they need. This may prevent people from engaging with the healthcare system or reaching out for care. Further, the historical challenges and negative experiences faced by Indigenous populations, including the residential school system, generated a disconnection from cultural knowledge, language, family and community, resulting in isolation and increased disparities. These challenges and experiences may also affect a person's trust of the system and Western medicine.

Trauma-informed care

To this day, Indigenous communities experience historical and intergenerational trauma. The social and economic inequities that Indigenous peoples experience are a result of systemic and structural racism. This contributes to the increasing frequency of the effects of trauma. Effects of trauma include anxiety, shame, emotional numbness and helplessness. These effects can impact a person's sense of safety and self-efficacy and the ability to regulate emotions.

Some inequities that impact Indigenous health are unemployment, poverty, child welfare apprehension, overincarceration and violence, which are all stressors associated with trauma. It is important to understand the origins of Indigenous trauma. This involves looking at historical events and the intergenerational effects that trauma has had on the community along with unrecognized grief.

Trauma-informed care aims to prevent retraumatization by acknowledging the history of traumatic events, impacts of intergenerational trauma and their connection to current barriers and challenges. It allows Indigenous peoples to be more involved in their own care. It is preventive and rehabilitative in nature and provides a culturally safe environment, built through collaboration and connection.

Health service delivery

A notable challenge for health service delivery for Indigenous peoples has been the limitation of the health funding model and reductions in funding for some health services. There have been longstanding challenges in appropriate and timely access to health services for Indigenous communities due to government policies, procedures and strategies.

Moreover, there is a lack of coordination and communication between providers in urban areas and local providers. This can lead to gaps in the care and supports a person receives. An example of these gaps is the noncompliance of [Jordan's Principle](#). This principle, as a legal obligation, was created to provide equitable healthcare, social services and support to First Nations children, but it has been neglected by the government, and it is estimated to have had an impact on more than 90,000 Indigenous children and young adults in need of care. In addition, First Nations communities have legally complained about the need to expand Jordan's Principle to support youth beyond the age of 18.

Continuity of care

A large percentage of Indigenous peoples live in remote areas, and this can affect their access to healthcare, to culturally appropriate care and to healthcare professionals. Inequitable access to healthcare is often listed as one of the most common challenges experienced by Indigenous populations. Primary care may be offered locally, but secondary or tertiary care often requires travel. The cost associated with travel or the need to leave the community can be a barrier to seeking care.

First Nations populations have shared concerns about accessing family doctors. An estimated 1 in 5 First Nations adults does not have access to a doctor. In addition, a high turnover of local doctors and nurses was identified as a barrier to building trust between an individual and a provider. Also, few doctors and nurses are trained in cultural sensitivity. In remote communities where access to follow-up care is limited, there may be challenges with information exchange such as communication between oncologists and local healthcare providers or sharing of medical records. This can impact the delivery and quality of care.

Culturally respectful healthcare providers

Due to discriminatory behaviours and a history of colonial trauma, there is a mistrust of the healthcare system. Some healthcare providers may lack cultural sensitivity or respectfulness of Indigenous cultural practices, traditions and values, which can cause further mistrust of the healthcare system. Barriers may arise if providers do not understand or address Indigenous peoples' concerns around cancer.

Information

A lack of cancer education, awareness and resources can lead to fear and decreased participation in cancer care. Limited resources available in Indigenous languages can increase misinterpretations and serve as a barrier to informed decision-making. Culturally safe education tools and materials can assist in increasing accessibility, receptiveness and participation in cancer care and can enable self-advocacy. A need was identified for more culturally informed resources regarding survivorship or recovery and palliative care, along with appropriate printed resources.

Support services

There are limited community-specific services and supports for Indigenous communities. Many supports and services are tailored for the general population or have a pan-Indigenous focus. Overarching supports for all Indigenous peoples is seen as unfavorable and does not work as it creates the idea that all Indigenous people are the same and have the same experiences.

Many programs are also short in duration or are discontinued due to lack of funding. This absence in sustainability of the services can challenge communities and put a strain on relationships, especially if the community cannot continue to deliver a service. Moreover, there are limited services and supports for families, friends and caregivers who may experience grief while providing support and care to people with cancer.

Caregivers

Indigenous caregivers experience poorer mental health and quality of life, and greater caregiver burden than non-Indigenous caregivers. This can be attributed to historical trauma, social marginalization, poverty and racism, all negatively impacting the ability and desirability of accessing caregiving services and resources.

Financial challenges

The financial burden associated with a cancer diagnosis, which can include costs of travel, accommodation, childcare and more, may lead some people to forego or delay treatment. The federal Non-Insured Health Benefits (NIHB) program provides coverage for travel and medication for First Nations people and eligible Inuit. Métis and other members of the Indigenous community are not eligible under NIHB and must find other financial assistance. First Nations people have expressed concerns around the difficulty to work through many levels of bureaucracy to access financial support. Further, funding for holistic and traditional treatment practices is hard to obtain.

Impact of travel

A large percentage of Indigenous peoples live in remote areas. Living in rural and remote communities often means less access to care and services and a need to travel. Travel can be a major challenge as it may lead to financial strains, disconnection from family and community, and additional stress related to navigating urban environments.

Although NIHB provides coverage for travel for some Indigenous individuals, it limits who can accompany the person living with cancer, which can cause greater harm in already difficult situations.

Interconnectedness is highly valued in many Indigenous communities and is a central pillar of wellness. Travel for care can disconnect a person from their family and community, which may lead to stress, isolation and reluctance to seek out services.

Communication channels

In many rural and remote parts of Canada, cellular and internet service can be very expensive and inaccessible to certain individuals or groups. Further, these channels may not be perceived as ideal over more traditional oral and visual communications.

Language barriers

There is limited availability of supports and information in Indigenous languages, which can increase barriers to cancer services. Terminology for cancer is not easily or consistently translated into Indigenous languages and can hinder communication. Older individuals who do not speak English or French may be at higher risk of not receiving the healthcare they need. They have expressed concerns about their family doctors failing to understand their culture and their language. Lastly, children may act as interpreters. However, children and youth may experience a burden by being interpreters for their families, particularly those with a family history of residential abuse.

Traditional spirituality and medicine

A holistic approach to health is important for many Indigenous communities, but this type of information and supports was not always available. Indigenous peoples have said that if too many Western remedies are used, they fear they will lose their traditional identity and beliefs. Exclusion of traditional medicine and practices have led to fear, mistrust, disempowerment and decreased participation in conventional biomedical cancer care. Having a culturally respectful clinical system can promote comfort and individual empowerment.

Opportunities and recommended tactics to improve supports

The opportunities and tactics shared in the table are for addressing gaps, barriers and challenges faced by Indigenous communities, but pan-Indigenous services and supports are not recommended. Every effort should be made to address these needs independently for First Nations, Inuit and Métis communities, where applicable.

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	<ul style="list-style-type: none"> • Increase availability and accessibility of information for Indigenous communities using multiple channels. • Improve gaps in service coordination through better information exchange. • Identify health disparities and barriers through Indigenous-specific data and create solutions. 	<ul style="list-style-type: none"> • Ensure culturally safe information is available. • Use plain language and culturally tailored graphics, illustrations and diagrams in content. • Ensure resources include stories from people with lived experience. • Ensure resources include information on both biomedical and traditional medicine. • Diet information and recommendations should consider the accessibility of fresh vegetables and fruit in remote communities as well as cultural relevance and personal preferences. • Include contact information for traditional healers in online cancer resources. • Increase information between Indigenous communities and cancer organizations.
Peer	<ul style="list-style-type: none"> • Increase availability and accessibility of peer supports for Indigenous communities through multiple channels. 	<ul style="list-style-type: none"> • Ensure peer matching includes people from various Indigenous communities. • Ensure services are tailored to respond to unique needs and history.
Practical	<ul style="list-style-type: none"> • Increase availability and accessibility of practical supports for Indigenous communities. 	<ul style="list-style-type: none"> • Improve communication between oncologists and healthcare providers through electronic tools. • Ensure healthcare providers receive cultural competency training. • Increase financial supports for Indigenous communities.

First Nations

There are about 1 million First Nations people living in Canada, corresponding to 58% of the total Indigenous population in the country and 2.9% of the total population of Canada. There is limited available data on cancer statistics for First Nations communities.

Gaps, barriers and challenges in care

Through the literature review and stakeholder engagement, specific gaps, barriers and challenges were identified for First Nations communities.

Cultural gaps in the cancer experience

First Nations communities have expressed interest in having more information on programs and services beyond the current services, supports and information offered by provincial and territorial health systems. This includes transportation services, accommodation and financial support. There is also a preference for printed materials over digital materials.

Key considerations for engagement

- There are over 630 First Nations communities recognized in Canada.
- The one-size-fits-all approach to services does not reflect the unique needs of each community.
- First Nations communities identified the need for services and supports that are culturally aware and sensitive.
- Transportation and financial strains are challenges for many First Nations communities living in rural and remote communities.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information for First Nations using multiple channels.	<ul style="list-style-type: none"> • Explore and identify the strongest channels for sharing information. • Ensure information is available in multiple languages.
Peer	Increase availability and accessibility of peer supports for First Nations with cancer through multiple channels.	<ul style="list-style-type: none"> • Support existing grassroots programs. • Develop partnerships to appropriately tailor peer supports to meet First Nations' needs. • Offer peer supports through multiple channels (including online channels). • Reach out to First Nations organizations in urban settings to increase First Nations peers. • Build and maintain partnerships with other providers to coordinate the delivery of services to communities. • Partner with First Nations organizations and services to ensure wraparound care and access.
Practical	Increase availability and accessibility of practical supports for First Nations with cancer.	<ul style="list-style-type: none"> • Develop partnerships to appropriately tailor practical supports to meet First Nations' needs. • Ensure that awareness and access of palliative care supports are available for First Nations. • Leverage partners to identify and recruit peers from First Nations communities as champions that can deliver co-developed programs and services. • Build capacity in the community to maintain programs. • Increase awareness in First Nations communities of available practical supports. • Ensure materials referencing travel to urban centres contain a list of First Nations community organizations in the area. • Educate healthcare providers on appropriate language when caring for First Nations with cancer. • Ensure support staff have cultural training. • Ensure availability of practical support information in organizational material. • Build and maintain partnerships with other providers to coordinate the delivery of services to communities.

Inuit

There are about 70,000 Inuit in Canada residing inside or outside of the homeland of Inuit Nunangat, which consists of 4 regions (Nunavut, Nunavik, Inuvialuit Settlement Region and Nunatsiavut), corresponding to 3.9% of the total Indigenous population in the country and 0.2% of the total population of Canada. There is limited available data on cancer statistics for Inuit communities.

Gaps, barriers and challenges in care

Through the literature review and stakeholder engagement, specific gaps, barriers and challenges were identified for the Inuit community.

Information

For many people in this community, visual language in communication was more important than using the Inuktitut language.

Access and capacity

There are limited resources locally across Inuit regions. Although health centres exist in Inuit regions, often they are over capacity and are forced to prioritize emergency care and immediate need. People are often discouraged from seeking healthcare except in an emergency. Accessing care in the South can be difficult and expensive, and challenges may occur around logistics for travelling. Further, the care or information provided to Inuit with cancer in Southern urban areas may not entirely align with the realities of living in the North.

Key considerations for engagement

- The logistical and financial challenges of accessing services in the South is a challenge for many Inuit.
- There are limited local health resources, which highlights the need for effective information and support along the cancer care continuum.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information for Inuit using multiple channels.	<ul style="list-style-type: none"> • Develop and leverage partnerships and expertise to tailor materials to include different dialects, understanding of Inuit culture and sensitivities, and acknowledgement of the role of traditional practices. • Leverage community supports that are already working within the geography to assist as co-designers and distributors of materials and information in Northern regions. • Place information at urban centres that Inuit frequent for care. • Focus on print materials as these are the preferred channels. • Ensure that information about the cancer experience is available.
Peer	Increase availability and accessibility of peer supports for Inuit with cancer through multiple channels.	<ul style="list-style-type: none"> • Partner with Inuit-specific lodges in urban centres as a hub for peer support programs. • Partner with Inuit organizations and services to ensure wraparound care and access.
Practical	Increase availability and accessibility of practical supports for Inuit with cancer.	<ul style="list-style-type: none"> • Work with partners to identify strategies to allow for tailoring at the community level. • Ensure awareness and access to palliative care supports for Inuit. • Leverage partners to identify and recruit peers from communities as champions that can deliver co-developed programs and services. • Build capacity in the community to maintain programs. • Increase awareness in Inuit communities of available practical supports. • Ensure materials referencing travel to urban centres contain a list of Inuit community organizations in the area. • Work with partners to identify supports that may enhance the experience for Inuit communities. • Ensure information on financial and other practical supports is available on organizational materials. • Educate providers on appropriate language when caring for Inuit with cancer.

Métis

There are about 624,000 Métis people in Canada, corresponding to 34.6% of the total Indigenous population in the country and 1.7% of total population of Canada. Métis people have communities across Canada, but the only legislated land base is in Alberta.

Gaps, barriers and challenges in care

Through the literature review and stakeholder engagement, specific gaps, barriers and challenges were identified for the Métis community.

Limited access to tailored services

In Canada, there is a lack of services designed for the Métis population. Often, Métis people are only given the option of pan-Indigenous services and supports. Many Métis people in Canada are also not given the opportunity to self-identify, compared with other Indigenous people, making it difficult to access Indigenous services. Many people may opt for access to services, information and supports designed for the general population.

There is great variability in Métis communities including the services needed or values held. Métis communities are blended with traditional spiritual views as well as Christian/Catholic beliefs. It is important that services provide space for all Métis spiritual views in order to create a culturally safe support system. Further, it was shared that Métis support groups are highly valued but usually unavailable in the community.

Key considerations for engagement

- There is an absence of Métis-specific services in Canada.
- There is great variability in Métis communities around values the community holds.
- Support groups and other methods for connecting people living with cancer are highly valued.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information for Métis people using multiple channels.	<ul style="list-style-type: none"> • Develop content that is culturally relevant and flexible to be tailored to each Métis person's unique needs. • Ensure in all information that Métis are identified as a unique people in Canada and should be distinguished from other Indigenous communities. • Leverage existing resources to develop tailored materials. • Use language that is culturally relevant, considers sensitivities and acknowledges the role of traditional practices. • Work with Métis partners to ensure content is culturally appropriate and reflects the diversity of Métis communities and culture.
Peer	Increase availability and accessibility of peer supports for Métis people with cancer through multiple channels.	<ul style="list-style-type: none"> • Explore alternative methods for people to access peer supports (for example, online peer supports). • Support existing grassroots programs. • Reach out to Métis organizations in urban settings to increase Métis peers. • Partner with Métis organizations and services to ensure wraparound care and access.
Practical	Increase availability and accessibility of practical supports for Métis people with cancer.	<ul style="list-style-type: none"> • Leverage community supports that are already working within the geography. • Ensure palliative care supports are available. • Work with partners to identify supports that may enhance the experience for Métis communities. • Work with partners to identify strategies to allow for further tailoring at the community level. • Leverage partners to identify and recruit peers from communities as champions that can deliver co-developed programs and services. • Build capacity in the community to maintain programs. • Increase awareness of practical supports available to the Métis community. • Ensure that materials referencing travel to urban centres contain a list of Métis community organizations in that area. • Ensure that information about financial and other practical needs is available. • Educate providers on appropriate language when caring for Métis with cancer. • Ensure cultural training for service providers engaging with Métis communities.

Urban Indigenous peoples

Many Indigenous people living in Canada live in urban areas where there is greater availability of healthcare resources, services and supports. The Indigenous population living in a large urban centre with more than 100,000 people grew by 12.5% from 2016 to 2021. In 2021, 44.3% (801,045) of Indigenous people lived in a large urban centre. However, the gap in services available for Indigenous people is still significant. There is limited available data on cancer statistics for urban Indigenous communities. In both rural and urban environments, there is a greater number of Indigenous people who report having less access to health services compared to their non-Indigenous counterparts. Several barriers are commonly reported including perceived quality of care available, wait times, discrimination and racism, along with lack of access to a family doctor. In urban environments, racism and discrimination are reported at higher rates. Similar to rural environments, service providers are often not trained in providing culturally safe and competent care, resulting in urban Indigenous peoples not receiving culturally appropriate services. It was reported that in urban hospital environments, it is more difficult to have traditional ceremonies in end-of-life care.

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Newcomers to Canada

Newcomer refers to someone who has been in Canada for a short time, usually less than 5 years. A newcomer can be an immigrant or a refugee who moved from their country of origin to Canada.

Introduction

Since the 1990s the population of recent immigrants has been rapidly increasing in Canada and it is the largest contributor to population growth. In 2021, 8.3 million people were, or had been, a landed immigrant or permanent resident in Canada, making immigrants account for about 23% of Canada's total population. There is limited data available on cancer statistics for newcomers to Canada. Newcomers to Canada may face similar challenges accessing cancer care as people who were born or have lived in Canada longer. But these challenges can be made worse by language barriers. Further, it is important to be aware of the heterogeneity of this group. Newcomers to Canada include groups of varying socioeconomic status, including economic immigrants, government-assisted refugees and asylum seekers. Economic immigrants may have transferrable educational and work experience that may place them in a better position upon arrival in Canada. Government-assisted refugees are provided with governmental support systems upon arrival to Canada, but refugee claimants and asylum seekers may not have the same supports.

Gaps, barriers and challenges in care

Stigma and shame

Many newcomer groups experience stigma and shame related to cancer, especially for cancers related to reproductive organs such as cervical cancer or prostate cancer. Further, in some cultures cancer can be considered taboo and the fear of shame from a diagnosis can prevent newcomers from accessing screening programs.

Competing priorities

When arriving to a new country, newcomers have many priorities such as finding housing and employment, arranging for school or setting up a bank account. These tasks tend to take priority over cancer screening or other preventive programs. For newcomers with cancer, it may be difficult to manage treatment without support for childcare or other priorities.

System navigation

Navigating the healthcare systems in Canada can be a challenge for many newcomers, as it may be different from healthcare systems in their home country. Newcomers primarily rely on family doctors to direct them to health services such as cancer screening. A delay in getting a family doctor can make it harder to navigate the system, and in the case of cancer screening, it can lead to a delayed diagnosis.

Healthcare providers

Many newcomer groups prefer to be treated by healthcare providers of the same race or ethnicity who demonstrate an understanding of their cultural needs. Healthcare treatment in a culturally safe and judgment-free zone is also very important to newcomers. Many organizations may not have equity-focused policies or may not prioritize time spent on building relationships and trust, to improve cultural awareness in care. Reports found that there is a lack of diversity in healthcare staff across Canada, resulting in healthcare providers and newcomers not sharing cultural experiences.

Newcomers with cancer have reported facing difficulties in building trust with healthcare providers who may not relate to their cultural backgrounds. Trust is additionally impacted by a breakdown in communication channels with studies finding that some newcomers felt their healthcare providers dismissed their healthcare needs, further decreasing their trust in the healthcare system. Gaps in communication can result in provider bias. Additionally, a lack of inclusion of newcomers in cancer research can result in healthcare providers making decisions based on assumptions.

A lack of cultural humility can impact patient-provider relationships. Healthcare providers may be unaware of cultural issues faced by newcomer groups such as gender preferences for their providers or a lack of autonomy experienced by women from male partners serving as “gate-keepers.” A lack of training in cultural competencies for providers was reported during engagement with stakeholders.

Lastly, a study found that provider discrimination negatively impacts a new immigrant’s psychological, social, environmental and overall quality of life. Discrimination and unfair treatment are related to poor self-reported health status and quality of life.

Trauma-informed care

Newcomers may experience higher levels of trauma. Refugees may experience many stressful and traumatic situations prior to, during and after migrating to a host country. This is in addition to the burden of physical, psychological and socioeconomic barriers to access basic needs such as healthcare, education and shelter. In addition, many refugees have experienced trauma related to war, which may involve fleeing their home countries to escape abuse and prolonged physical and emotional distress. This can affect their physical and mental health. Trauma-informed care in newcomers can help to prevent retraumatization by acknowledging their experiences and providing a safe environment across the continuum of care.

Fragmented resources and operations

While resources on cancer information and support are available for newcomers, these resources are often fragmented across the country and across different organizations, all operating in silos.

Information

Cancer information is often only available in English or French and can include complex medical terms. The lack of multilingual information sources can result in newcomers accessing cancer information from unreliable sources, which can increase beliefs in myths and misinformation.

Language barriers

Language barriers can impact accessibility to cancer information and support for newcomers. Language barriers may result in newcomers feeling isolated, failing to understand medical instructions and being unable to share concerns or ask questions regarding their diagnosis and treatment. It can also hinder a newcomer's ability to advocate for themselves or make decisions related to cancer care.

Interpretation services

Interpretation services or family interpreters can help reduce language barriers. However, family interpreters may filter or block information related to a prognosis or they may be prone to errors as they are not trained as interpreters in a medical setting. Further, when family members are interpreting, they may alter the messaging to soften the news or hide a poor prognosis. Newcomers have also expressed discomfort when disclosing information when an interpreter is present. Therefore, they may not communicate all their needs. Lastly, children may act as interpreters. But children and youth may experience a burden by being interpreters for their families, particularly those with family who may have experienced trauma.

Social support

Newcomers may not have an established social network of family or friends in Canada. This can impact their ability to adapt to a society that is new to them. For newcomers with cancer, an absence of a social network can hinder the ability to navigate healthcare and support services systems. Further, a lack of social network limits the benefits of support such as assisting with childcare needs and transportation and accessing cancer information.

Support groups

For newcomers with cancer, a lack of cancer support groups can result in the individual feeling isolated, overwhelmed and defeated by the cancer experience. Support groups can help reduce mental and physical stresses of a cancer diagnosis.

Caregivers

For caregivers, a lack of support groups, in addition to unmet cultural needs such as language barriers, can hinder their ability to care for a person with cancer. Studies found that immigrant parent caregiving roles were challenging when they were unable to learn the complex medical terminology or understand the treatment process. Support groups can be helpful in directing caregivers to caregiving services and resources needed.

Counselling services

For many newcomers to Canada, particularly people who belong to refugee groups or are asylum seekers, the journey to Canada can be a traumatic experience. The burden of a cancer diagnosis can make this experience worse. Access to counselling and psychotherapy services without financial costs can be beneficial to newcomers to overcome the mental stress and turmoil. However, mental health can be considered taboo in some cultures, which can make it a challenge for newcomers to access mental health supports and services.

Financial challenges

Unmet financial needs and lack of access to health insurance can impact a newcomer's access to cancer services and attendance for cancer treatment. After arriving in Canada, it may take significant time before newcomers receive health insurance. Without health insurance, a fear of out-of-pocket expenses may prevent newcomer groups from accessing cancer services or complementary therapies. Newcomers who are self-employed or in a job without access to paid sick days risk losing income to attend healthcare appointments. Further, some newcomers in precarious employment conditions may not be in a position to file taxes, which can hinder access to government tax credits and drug programs.

Impact of travel

The impact of travel for newcomers to Canada is worse in rural areas. The limited availability of healthcare access in rural areas in combination with less transportation infrastructure makes it difficult for newcomers who rely heavily on public transportation. Transportation can also be an issue if newcomers with cancer are matched with a healthcare provider in a different region and they do not have the funds to travel between regions.

Key considerations for engagement

- Language and cultural barriers can result in a misunderstanding of information and support services and lead to people feeling isolated in the system.
- Tailored communication approaches that reach the community directly are the most successful.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability, accessibility and cultural relevancy of information using multiple channels and delivery through multiple languages.	<ul style="list-style-type: none"> • Partner with multi-sector stakeholders that provide services to newcomers to streamline the provision of cancer information. • Collaborate with stakeholders involved in providing cancer information to develop a collective repository of information. • Partner with faith-based leaders, schools and youth to engage with communities and provide cancer information. • Ensure cancer information resources are available in multiple languages. • Develop culturally relevant and sensitive communication materials using simple language, graphics and other visual representations. • Leverage existing resources developed by organizations that cover cultural and language considerations for healthcare staff interacting with diverse populations.

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Peer	Increase availability and accessibility of peer supports through multiple channels for newcomers to Canada.	<ul style="list-style-type: none"> Partner with community centres and cultural associations to establish cancer support groups. Offer summer camps and recreational programs for children with cancer and their caregivers. Offer support services in multiple languages. Ensure peer support platforms have a group dedicated to newcomers.
Practical	Increase availability and accessibility of practical supports for newcomers to Canada.	<ul style="list-style-type: none"> Partner with organizations that support or represent newcomers to identify strategies to support practical needs and ensure newcomer perspectives are captured in service design and programming. Design financial assistance programs to help reduce financial barriers and increase awareness of available programs. Ensure that organization information on financial and other practical needs are available in multiple languages. Conduct needs assessments to identify practical needs of newcomers with cancer. Ensure system navigation support to newcomers within the healthcare and social services sectors. Commit to greater diversity in the health and social services sector. Design training programs for healthcare providers that address implicit bias and provider bias. Expand network of partners to include newcomers who are qualified healthcare practitioners in their country of origin. Increase the use of interpreters that have been vetted against quality assurance standards. Engage with healthcare providers to support the delivery of culturally sensitive care across communities. Leverage existing resources developed by organizations that cover cultural and language considerations for healthcare staff interacting with diverse populations. Ensure awareness of counselling services.

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Older adults

Older adults are defined as people aged 65 years and older.

Subcommunities

- youngest-old (65 to 74 years)
 - middle-old (75 to 84 years)
 - oldest-old (85+ years)
-

Introduction

Canada's population of older adults is growing very quickly as Canadians live longer and healthier lives. As of 2022, there were over 7 million people aged 65 years and older in Canada, making up 18.8% of the total population. The risk of developing cancer increases with age. Given the growing and aging population, there will be a significant increase in the number of older adults who are diagnosed with cancer in the coming years. In 2021, about 63% of cancer cases were projected to be diagnosed in older adults.

Though older adults make up the greatest proportion of new cancer diagnoses, many older adults are not receiving the same information and options for treatment as younger people. Ageism – stereotypes, discrimination and prejudice based on age – in the healthcare system is a major contributor to cancer disparities in older adults. Healthcare providers may limit discussion of treatment with older adults because of their own assumptions or biases about age and cancer. As a result, older adults have many unmet needs in cancer care such as how to cope with fear, adequate information on side effects and chances for a cure, and education needed to make informed decisions about their care. This may lead to over-treatment and under-treatment and poorer outcomes in older adults.

Gaps, barriers and challenges in care

Comorbidities and loss of function

Older adults with cancer are more likely to also have other diseases or conditions (comorbidities) than older adults without cancer. Many older adults with cancer may have at least one comorbidity that may impact their treatment. Further, older adults may face self-care and loss-of-function challenges.

Home care

A study found that the use of home care in older adults peaks in the first month after cancer surgery, decreases to a new baseline at the one-year mark, and then remains stable for up to 5 years. The same study found that about 11% of people with cancer who didn't initially require home care services used these services for 5 years after surgery. This indicates an increased need for healthcare support and loss of independence with time, and that acute home care needs may not accurately reflect long-term needs.

In another study comparing self-ratings of people with cancer to their caregivers, caregivers rated older adults with cancer as having poorer physical function and mental health and needing more social support. Many caregivers in this study also expressed caregiver burden.

Lastly, many older adults with advanced cancer would prefer to die at home. In Canada, the majority (71%) of people with cancer die in hospital, while only about 10% to 13% die in their own homes. This suggests that there is a need for proper support systems to allow older adults with cancer to remain in their own homes near the end of life.

Information

Many older adults with cancer do not receive sufficient information about their diagnosis. Often, the family gets informed before the individual with cancer themselves. This may be due to the doctor's belief that older adults with cancer are less able to cope with a cancer diagnosis. Another factor can be declining literacy levels, as cognitive levels decline with age. But family members do want to inform people with cancer, even if they are frail, aged or have neurological disorders.

Decision-making preferences

Older adults with cancer may have different preferences for their involvement in decision-making. Studies found that a similar proportion preferred a passive or active role, with fewer preferring a collaborative role. However, a study conducted in the UK found that older women with breast cancer preferred a collaborative decision-making approach with their healthcare providers regarding chemotherapy. Many older adults appreciate the opinions of their cancer specialists and general practitioners, especially guidance about the decision to accept or reject treatment. The recommendation from clinicians may influence treatment decisions. In a study from the UK, many women shared complaints about information overload and had difficulty using the information provided in reaching treatment decisions. Having a caregiver during appointments helped them retain information and receive emotional support. They also said that decision-making about treatment involved consideration of their general health, age and family input.

Psychosocial needs

Older adults often have unmet psychological needs, and psychological support is needed before cancer treatment begins. Older adults with cancer often lack social supports, and this is more prominent in people who are single, racialized, have few friends or children, or have a high symptom burden (this could include the number of symptoms they're having, the severity of their symptoms or the impact of their symptoms on their quality of life).

Trauma-informed care

The risk of having experienced trauma increases with age. An estimated 70% to 90% of older adults have experienced a traumatic life event. Forms of trauma vary widely but can include the sudden death or serious injury of a loved one or the life-threatening illness or death of a spouse or child. Trauma reactivation, or experiencing reminders of trauma, may also occur with increasing age and may be worsened by illness and stressful events. As a result, there is a need for trauma-informed care among older adults, particularly in hospice and palliative care settings and in the cancer context.

Financial challenges

Older adults with cancer can have financial burdens from direct and indirect costs associated with treatment. In one study, 27% of older adults with newly diagnosed cancer reported financial distress at the time of initial presentation to an oncologist. This disproportionately impacts people from the Black community, people with disabilities, those who are unemployed, and people who had lower educational levels. These people were more likely to report depression and impaired health-related quality of life at the time of diagnosis. Financial burden and reduced income may also be a challenge for family members providing care to people with cancer.

Impact of travel

Transportation to and from appointments may pose a challenge as many older adults no longer drive or own a vehicle. As a result, many older adults rely on family and friends to provide transportation, or use ride share services, public transportation or transportation services offered by organizations. However, older adults report challenges with these transportation options, including feeling dependent on others, difficulty asking family or friends for rides, stigmatization or embarrassment, limited rides and the high cost of gas, parking and services. Insufficient public transportation infrastructure and the physical challenges of travelling long distances also create challenges during cancer treatment. Older adults in rural and remote communities have more limited transportation options compared to those in urban areas.

Treatment options

Older adults with cancer may not be offered the same treatment options as younger people. One reason for this is older adults often have more comorbidities, which could make treatment risks outweigh benefits. Ageism in healthcare also plays a role as healthcare providers may limit discussion of treatment with older adults because of their own assumptions or biases about older age and cancer. Studies have shown people with cancer over 70 years of age were less likely to receive radiation therapy and chemotherapy. Given the variations within this group, older adults with cancer should have access to a geriatric assessment, which is a health measurement tool that provides tailored information and recommendations that can inform treatment plans. Results from a systematic review found that geriatric assessment in cancer care is associated with reduced treatment-related toxicity and complications and improved treatment completion and patient-centred outcomes.

Caregivers

Caregivers of older adults often must discuss and plan for death. This includes reflecting on their future relationship with the individual even if they are being treated with the hope of curing the person. Evidence shows that caregivers also have many psychosocial issues, financial burdens and reduced income. Caregivers often experience higher levels of burden and a lower quality of life compared to the general population.

Caregivers' experiences and unmet needs often vary due to differences in age, culture, healthcare system and support systems. For example, adult children who are caregivers to their older parents often report more negative experiences in health, finance, change of schedule, self-esteem and spiritual well-being.

Key considerations for engagement

- Older adults with cancer want to be able to easily access the information and supports they require in appropriate formats.
- Older adults with cancer want to feel supported, even if they have no caregivers present in their lives.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information for older adults and their caregivers using multiple channels.	<ul style="list-style-type: none"> • Develop tailored materials (e.g. managing comorbidities, self-care, financial management, multi-disciplinary). • Develop printed resources available in large print that is easy to read. • Develop outreach strategy to disseminate resources to existing spaces that older adults frequent (e.g. community centres, seniors' programs, libraries, shopping malls, clinics, pharmacies). • Ensure information about financial management for older adults is available through multiple methods such as online, print and mail. • Develop online content as internet use for older adults is increasing. • Use digital storytelling on video platforms by older adults to tell stories about their experience with cancer.
Peer	Increase availability and variety of peer supports for older adults and their caregivers through multiple channels.	<ul style="list-style-type: none"> • Ensure peer matching includes older adults of all ages. • Ensure alternative methods are available for older adults to access peer matching. • Partner with support programs to enhance offerings that provide companionship to older adults. • Create a support framework for older adults that existing programs can leverage for their programming. • Increase group or one-on-one activities through various channels such as in person, by phone or online video conferencing tools and social networks.
Practical	Increase availability and accessibility of practical supports for older adults and their caregivers.	<ul style="list-style-type: none"> • Ensure that practical support service providers receive required training to listen and refer people to supports related to their common concerns. • Increase awareness of financial supports for older adults. • Collaborate with partners to deliver self-care and respite supports. • Increase access and awareness to interventions to enhance spiritual well-being to help caregivers find meaning in their experience and improve quality of life and mental health.

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Racialized communities

Racialized communities refers to people who have racial meanings attributed to them as a group in ways that negatively affect their social, political and economic lives. Race is a social construct that can change over time and place.

The term may include, but is not limited to, Black ethnicity including African or Caribbean ancestry, South Asian, Chinese, Arab/West Asian, Southeast Asian, Filipino, Latin American, African, Caribbean, Korean, Japanese and Pacific Islander.

For the Canadian Cancer Society's work, and for the work of many organizations in Canada, this population does not include Indigenous peoples.

Introduction

As of 2021, about 9.6 million people from over 450 ethnic origins and ancestries reported that they are part of a racialized community, making up 26.5% of the Canadian population. The real extent of the disproportionate impact of cancer on racialized communities in Canada isn't yet known due to a lack of race-based data. However, international research suggests that cancer incidence and mortality differ among racialized communities compared to the general population.

Racialized communities experience inequities in health and cancer care due to the barriers embedded in the structures of the current healthcare system including their experiences with individual, systemic and structural racism. Racialized communities report concerns about not understanding their cancer diagnosis, which is associated with a lack of access to culturally relevant cancer information. They also experience unmet cancer care needs including psychosocial, emotional, informational, socioeconomic and practical needs leading to poorer health outcomes. It's important to recognize that within these groups there are variable levels of income, employment security, education, adaptation into a new culture and trust in the healthcare system.

Gaps, barriers and challenges in care

Stigma and shame

Many racialized groups experience stigma and shame related to cancer, especially for cancers related to reproductive organs such as the cervix or prostate. This can result in people avoiding seeking social support services, accepting help from caregivers or sharing psychosocial concerns with doctors. Further, stigma is found more for “below-the-belt” cancers (for example, cervical or prostate cancer).

System navigation

Members of racialized communities report difficulties in navigating the health system pertaining to who to consult or how to access specialist treatment. A study found that African American breast cancer survivors reported feeling lost regarding information across various health-related topics. Challenges with navigation and a limited coordination for cancer care can lead to delays in treatment and long wait times for members of racialized groups. Racialized people living in rural areas are less likely to be diagnosed with cancer at an early stage due to limited access to services near their communities. This highlights the need for better system navigation in rural areas.

Healthcare providers

Low levels of engagement between patient and provider can lead to limited understanding of patient diagnoses for providers and reduced patient trust and confidence in talking with their providers. Patients from racialized groups reported feeling “disempowered” when receiving paternalistic information from providers. An example of this scenario is a racialized individual who is diagnosed with cancer at a later stage, despite having visited the emergency room multiple times. This could be the result of a healthcare provider’s implicit bias leading to mistrust or an underestimation of the extent of the person’s pain or symptoms.

There is also a strong desire expressed by members of racialized communities for care and interactions with healthcare professionals who speak the same native language or share cultural backgrounds. In some situations, healthcare providers are uninformed about cultural needs such as traditional diets and medicines, healing rituals and complementary therapies. Healthcare providers may also be insensitive to the person’s needs related to the gender of the provider and methods of delivering information.

Trauma-informed care

Systemic and structural racism faced by racialized communities can lead to post-traumatic effects that can impact decisions on the individual’s health. Trauma-informed care centres must promote cultural safety, trust, collaboration, peer support, empowerment and cultural and gender support for racialized communities. Microaggressions, overt racism and intergenerational racism experienced by racialized communities can lead to increased exposure to trauma and aggressive lines of treatment.

Language

Language barriers are often present in racialized communities, including people who have lived in Canada for over 5 years and feel uncomfortable conversing in English or French.

Information

One of the highest unmet needs among racialized communities is information. The use of complex language in information sources and limited visual representation of information contributes to this unmet need. Further, the lack of visual representation of cancer symptoms in racialized communities has often led to symptoms being missed or dismissed. For racialized communities, cancer information that is highly sought after is information related to diet, side effects and secondary cancer prevention. Many racialized people with cancer prefer to consume traditional foods and believe in their traditional healing powers. This information is often neglected in reputable cancer information sources, resulting in people turning to social media or the internet, which can lead to reading myths and misinformation.

Psychosocial needs

Members of racialized communities report unmet psychosocial needs related to social well-being and loneliness, and emotional symptoms such as depression, sadness, anxiety and stress. This can lead to disparities in psychosocial stress, difficulties in processing the emotional aspect of the cancer experience and feelings of isolation.

Support groups

Members of racialized communities may be less likely to seek or receive peer support, although racialized people have shared the important role of providing support to their communities after a diagnosis. Further, racialized people with cancer may benefit from community-based stress-management interventions.

Counselling

For many people in racialized communities, access to affordable, professional counselling that caters to their specific needs is limited. People may turn to informal counselling through their social network or counselling from grassroots organizations within the community. This can lead to a lack of consistent or specialized counselling.

Caregivers

There are limited professional counselling supports for caregivers from racialized communities. There are also challenges with navigating the supports that do exist and significant levels of stress in caregiving.

Financial challenges

People with cancer in racialized communities are disproportionately impacted by financial hardships during the cancer experience. A Canadian study found that although not all racialized people live on a low income, economic racism contributed to inequitable experiences. A study found that low-income African American cancer survivors in the US reported food insecurity, utility shutoff, inability to travel to receive care and having a lower quality of life. Care-related financial barriers and loss of health insurance were also reported in interviews. Further, some members of racialized communities in precarious employment conditions may not be in a position to file taxes, which can hinder access to government tax credits and drug programs.

Impact of travel

Travel to treatment can be time consuming and expensive for racialized people with cancer and their caregivers, particularly people from a lower socioeconomic status. Distance of travel could create a barrier to care. While initiatives exist to support people with travel to treatment, there is room for improvement in terms of program responsiveness and navigation.

Survivorship care

People in racialized communities experience insufficient access to survivorship information, which can lead to feelings of being lost in the transition from specialty to primary care. Racialized people with cancer may be less likely to receive comprehensive survivorship care.

Fatalism

There is a belief among many members of racialized communities that cancer is untreatable and fatal. This belief may deter people from seeking cancer information and treatment. Further, this is also fuelled by fears around cancer progression and recurrence, which can cause further distress and depression.

Key considerations for engagement

- Structural and systemic racism have contributed to the inequities in health and cancer care among racialized communities.
- Racialized communities with cancer face different challenges with the Canadian system because they don't see their culture reflected or considered in the care they receive.
- Racialized communities want to be able to easily access resources and culturally relevant support and information in appropriate formats.
- Tailored communication approaches that reach racialized communities directly are the most successful.
- Racialized communities are a heterogeneous group with unique challenges that need to be further explored within communities to achieve equitable care.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability, accessibility and cultural relevancy of information using multiple channels and delivery through multiple languages.	<ul style="list-style-type: none"> • Partner with racialized communities and grassroots organizations and groups to deliver educational resources and informational campaigns. • Engage with racialized communities, organizations serving racialized communities and groups including spiritual establishments on an ongoing basis to acquire up-to-date understanding of the type of information needed, along with the best ways to deliver them to community members. • Include members of racialized communities in the design and delivery of cancer information. • Ensure information is delivered in a timely manner and in appropriate languages. • Offer navigation support through trained resource coordinators to allow people with cancer to identify and access necessary information resources.
Peer	Increase availability and accessibility of peer supports through multiple channels for racialized communities.	<ul style="list-style-type: none"> • Connect siloed services through a shared information repository or platform to connect organizations providing cancer support services for racialized communities. • Partner with organizations serving racialized communities to offer peer support groups where people with cancer share cultural backgrounds or treatment types. • Include members of racialized communities in the design and delivery of cancer support services. • Deliver services to racialized communities through multiple methods such as a mobile clinic and virtual services. • Offer navigation support through trained resource coordinators to allow people with cancer to identify and access necessary peer support resources.

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Practical	Increase availability and accessibility of practical supports for racialized communities.	<ul style="list-style-type: none"> • Partner with racialized communities and organizations serving racialized communities to better support the communities' practical needs. • Increase awareness to affordable, professional counselling to racialized communities with cancer. • Review eligibility criteria for financial supports and increase awareness of supports. • Review financial requirements for services. • Establish the criteria to improve the quality of customer service in existing supports. • Deliver services to racialized communities through multiple methods such as a mobile clinic and virtual services. • Integrate the use of culturally relevant and sensitive care elements into care of people with cancer. • Increase awareness of counselling for both the person with cancer and caregivers. • Offer navigation support through trained resource coordinators to allow people with cancer to identify and access necessary practical support resources. • Offer employee training particularly for service providers to address implicit biases regarding income and financial and practical barriers faced by racialized communities. • Offer training in culturally sensitive practices for service providers. • Offer a training curriculum for providers to offer cancer survivorship plans that are culturally sensitive.

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Rare cancers

Rare cancer is defined as cancer that is diagnosed in less than 6 of every 100,000 people in Canada each year.

Introduction

Little information exists on rare cancers, and the cumulative burden has not been explored in Canada. Rare cancers account for up to 20% of new cancer cases in Canada. Some research suggests that rare cancers are most common in children and young adults, with survival rates being lower than survival rates for common cancers.

Due to a lack of familiarity and clinical knowledge, finding and diagnosing rare cancers can often be delayed, making the cancer harder to treat, furthering inequities. There is also a lack of treatment options for rare cancers, and many healthcare providers don't adequately understand the rare cancer types or available treatments. As funding and research are limited, these gaps in knowledge and practice continue, resulting in heightened unmet needs in people diagnosed with rare cancers. Inconsistent use of rare cancer reporting methodologies causes additional challenges by creating gaps in the collection of information.

Some might be surprised about the cancer types that meet the definition of a rare cancer. In Canada, rare cancers include but are not limited to Kaposi sarcoma, ureter, penile, eye and orbit, bones and joints, salivary gland, mesothelioma, gallbladder, anus, anal canal and anorectum, small intestine, soft tissue (including heart), male breast cancer, uterine, testicular and laryngeal cancer.

Gaps, barriers and challenges in care

Awareness

Finding and identifying rare cancers can be delayed. Individuals and clinicians may be unaware of early rare cancer symptoms, and there may be a prolonged period of testing before a diagnosis is made. This delay can lead to poorer health outcomes.

Information

Information for people with a rare cancer is often extremely limited. Print information is often scarce in cancer centres, and online information about diagnosis, staging and disease management can also be incomplete or incorrect. Cancer websites may not have an exhaustive list of healthcare needs, such as supportive care, spiritual needs and psychological needs that are specific to people with rare cancers.

Social and emotional support

Rare cancer support services are unavailable or limited since there are not many people with the same type of rare cancer. This can lead to people with rare cancer feeling isolated, confused and stressed.

Psychosocial needs

Evidence shows that people with rare forms of cancer can have higher rates of depression and anxiety after cancer treatment. They can have difficulty coping with uncertainty, difficult treatment decisions, long surgery wait times, fears about surgical complications, potential metastases (spread of cancer) and death. Lastly, studies show they have higher rates of unmet needs, which can cause profound social effects, isolation and psychiatric conditions.

High symptom burden

Some people with rare cancers have a high symptom burden (this could include the number of symptoms they're having, the severity of their symptoms or the impact of their symptoms on their quality of life). Pain, shortness of breath and fatigue were the most reported symptoms.

Financial challenges

People with rare cancer may have financial burdens due to the cost of their treatment. In some instances, treatment costs may not be covered by the publicly funded system, resulting in out-of-pocket costs. These costs are highest during treatment, can decrease over time, and vary by individual due to clinical factors such as the type of treatment. People diagnosed with rare cancers may have to put their employment on hold, which can impact their financial situation and quality of life.

Caregivers

Caregivers of people with rare cancers can have a variety of unmet needs, which strongly predicts their overall quality of life. The physical and mental health of people and their caregivers are often related, and sometimes the psychological burden on caregivers is greater than the burden on people with cancer, due to less practical and emotional support from friends and professionals.

Trauma-informed care

The information and social support on rare cancers is often limited and sometimes unavailable. This may contribute to increased feelings of alienation, confusion and stress. There is a lack of evidence of trauma-informed care in people living with rare cancer. This makes it hard for healthcare providers to understand the value of trauma-informed care in people with rare cancer.

Key considerations for engagement

- People with rare cancers want to be able to easily find resources and testimonials specific to their cancer type.
- People with rare cancers want to find peers that understand the complexities of being diagnosed with a rare cancer.
- People with extremely rare cancers want resources specific to funding for treatments.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information using multiple channels for people with rare cancers and their caregivers.	<ul style="list-style-type: none"> • Increase information on commonly reported symptoms. • Increase information about rare cancer including prognosis, treatment, palliative care and end-of-life care. • Use plain language on websites and other cancer information materials. • Create a database with national and international resources for people with rare cancer. • Use digital storytelling on video platforms to tell stories about their experience with a rare cancer.
Peer	Increase availability and accessibility of peer supports using multiple channels for people with rare cancers and their caregivers.	<ul style="list-style-type: none"> • Recruit volunteers from across Canada to build a network of peers matching people with the same rare cancer type where possible. • Partner with other organizations to build peer matches. • Create a discussion forum for rare cancers on online support programs. • Develop seamless referrals to established support groups both online and in person for rare cancers.
Practical	Increase availability and accessibility of practical supports for people with rare cancers and their caregivers.	<ul style="list-style-type: none"> • Increase availability of, knowledge of and access to financial assistance programs. • Ensure resources are available at regional cancer centres specializing in rare cancer treatment. • Increase awareness of how to access medications for people with rare cancer.

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Rural and remote communities

A community is considered rural or remote when it has a population of 10,000 or less or because geography has limited people's access to healthcare facilities and services.

Introduction

About 6 million people in Canada reside in rural and remote areas. This makes up about 16% of the population. In Canada, the incidence rates of most cause-specific cancers were lower in rural areas than urban areas. However, people in rural and remote areas of Canada have higher cancer mortality rates. Additionally, only 9.3% of family doctors practise in rural areas, leading to increased disparities in healthcare services.

Living in a rural or remote area can negatively influence socioeconomic, environmental and occupational health determinants, potentially leading to poor health outcomes. People with cancer and their caregivers who live in rural areas face unmet psychosocial and informational needs and have poorer health outcomes and long-term survival.

Gaps, barriers and challenges in care

Lack of access

There is limited access to cancer specialists for people living in rural parts of Canada. Therefore, family doctors often fill this gap. Additionally, people living in rural areas face challenges accessing cancer care including access to transportation, time, accommodation if needed and financial burden. Early morning appointments may require travel through the night, and treatment that occurs over several weeks can create additional barriers. All of these factors may have an impact on the treatment a person chooses.

Communication

For people living in rural and remote areas, overall satisfaction and cancer experience was affected by their disconnect with their doctor or care team. Communication played a large role in this disconnect. In one report, women with breast cancer said they had difficulty accessing appropriate information from their family doctors, citing poor communication between cancer treatment centres and specialists to their family doctors. Lack of communication between local and specialized clinics can complicate the process of accessing care for people with cancer in rural communities, while collaboration and communication can reduce barriers and make healthcare services more readily available.

Virtual care

Having access to telemedicine can improve access to cancer care and support services. However, access is not equal among people living in rural and remote areas mainly due to limited or unreliable access to the internet.

Social and community support

Many cancer survivors living in rural areas want to connect with other survivors to understand their illness and minimize fear. In one study, men expressed the belief that there were more support groups available to women, and they felt less supported than women.

Financial challenges

Many financial challenges exist for people seeking care such as costs associated with lodging, travel, food and medication. Additional costs can include arrangements around employment or possible unemployment.

Caregivers

Caregivers living in rural and remote locations may experience different challenges than urban caregivers including transportation challenges and social or geographic isolation.

Trauma-informed care

Evidence shows higher odds of experiencing issues accessing healthcare in rural and remote regions when compared with urban areas. As cancer itself can be a traumatic experience, not having access to care can increase the physical, emotional and financial burden on individuals living with cancer in rural and remote communities. This highlights the need for delivering timely and accessible trauma informed care in this community.

Palliative care

Palliative care aims to relieve discomfort and improve quality of life at all stages of cancer. Accessing palliative care can be extremely difficult for people living in rural and remote communities for a variety of reasons. First, there is a lack of available services as only 2.3% of Canada's healthcare providers who specialize in palliative care work in rural communities. Additionally, travel-related issues and costs can make it difficult for people living in rural and remote communities to access palliative care in urban centres. Rural residents are more likely to be admitted to an acute-care hospital numerous times, make more emergency department visits and be admitted to ICUs more often at the end of life.

Information

In one study, it was found that men who live in rural areas are less likely to seek information about their illness and participate in decision-making around treatment. Additionally, a study from the Canadian Breast Cancer Network found that many women were often unhappy with the experience they had in the services provided in rural areas. They said that often the information and services available were unhelpful or outdated, requiring them to set aside time to search for resources and services on their own. They also said that they would prefer to receive information packages from their healthcare team upon cancer diagnosis. This includes information about medical resources, support groups, psychosocial support, treatment and side effects. Lastly, in rural and remote areas, there can often be limited internet availability or poor internet speeds.

Psychosocial needs

Many people with cancer in rural communities said that emotional management was a significant concern. People with cancer often feel a range of emotions but can have difficulty recognizing, describing and managing them. Psychosocial follow-up care was also identified as important to breast cancer survivors living in rural areas. Further, there may be limited mental health services for people with cancer living in rural and remote communities, which can result in poorer health outcomes.

Key considerations for engagement

- People with cancer who live in rural and remote communities want to be able to easily access resources including those specific to financial concerns.
- People with cancer who live in rural and remote communities want to have models and approaches to support that are responsive to their local environment.

Opportunities and recommended tactics to improve supports

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Information	Increase availability and accessibility of information using multiple channels for people living in rural and remote communities.	<ul style="list-style-type: none"> • Develop tailored materials around needs such as travel, accommodation and financial assistance. • Use both mobile-friendly and printed materials. • Use culturally tailored educational messaging to inform racialized communities living in rural areas. • Use plain packaging for mail delivery of information to respect privacy. • Engage communities by setting up information booths at local events. • Ensure that information about financial and travel planning for rural and remote people is available online. • Use props and other visuals to supplement print materials and presentations. • Create digital storytelling on video platforms focusing on rural experiences.

Type of support	Opportunities for addressing gaps	Recommended tactics to address gaps
Peer	Increase availability and accessibility of peer supports using multiple channels for people living in rural and remote communities.	<ul style="list-style-type: none"> Recruit peers located in rural and remote settings. Increase support groups for men in rural areas. Ensure that peer facilitator training includes additional people from rural and remote communities. Ensure a variety of methods for people to access the virtual peer matching (e.g. by phone). Support people with cancer and caregivers through available local community supports such as community centres. Increase awareness of financial programs.
Practical	Increase availability and accessibility of practical supports for people living in rural and remote communities.	<ul style="list-style-type: none"> Partner with local organizations to enhance financial supports for rural and remote communities. Partner with local organizations to enhance practical supports for rural and remote communities. Develop resources and training to inform rural and remote healthcare providers about cancer-specific challenges (e.g. certified training). Increase awareness of telemedicine for care. Provide information on early access to palliative care services. Develop a system that can be used for people with cancer to report problems to a healthcare team. Identify and increase awareness of technological tools to distribute health resources.

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Recommendations

Through the underserved communities project, 5 overall recommendations for organizations that provide cancer information and support services were developed to ensure that people within each underserved community receive appropriate information, supports and resources. These recommendations can be applied by other organizations that support communities that are underserved. The success of these recommendations and this work overall is dependent on leadership at the highest level in organizations to champion this work and create accountabilities throughout the organization. Additionally, the scope of the barriers faced by communities that are underserved are vast and organizations will need to work together to address the issues.



Conduct dedicated training for staff

- Identify training gaps and needs across the organization and opportunities to bring staff and volunteers together for dedicated training.
- Identify roles including management and staff who design, guide and deliver information, support and practical services.
- Conduct mandatory training to ensure staff have an understanding of gaps and barriers that underserved communities face, as well as anti-bias training to educate staff on how to work with and engage various communities.
- Develop and implement a strategy to evaluate the impact of training on staff.
- Build training into onboarding for new staff and offer further training over time as needs change and new information becomes available.



Evaluate internal capacity to conduct meaningful engagement with communities

- Assess readiness of resources within the organization's priorities and initiatives.
- Assess the readiness and capacity of staff to undertake new work with underserved communities.
- Identify resources for this work and determine its long-term sustainability.



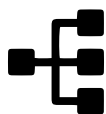
Prepare for meaningful engagement with communities

- Identify a list of partners for each underserved community that engages in similar work.
- Define what is needed from the partnership (for example, establishing an advisory committee or developing a channel to exchange information with the community).
- Train staff on the needs and sensitivities of the community, cultural competency and inclusive best practices before engagement.



Engage and co-design with communities to validate needs, opportunities and tactics

- Engage with communities to prioritize and build solutions based on their needs.
- Be present within the communities without an “agenda.”
- Build trust within communities by prioritizing presence with the communities and joining community events.
- Ensure involvement of the communities from the onset of any project.
- Ensure funding is available to cover the expenses, time and resources involved.



Co-create an evaluation framework to monitor the impact of information and supports

- Set clear standards and expectations to measure performance and improvement together.
- Develop metrics and targets to monitor strategies and tactics implemented for each underserved community.
- Engage communities regularly to ensure services continue to meet the communities' needs.
- Share monitoring and evaluation results with the community and write the narrative on impact together.

Conclusion: Working together for change

People with cancer face many challenges as they navigate their cancer experience. They have many needs including physical, emotional, social, psychological, informational, spiritual and practical needs. Many of these needs are complicated and can be worsened through systemic disadvantages for reasons including but not limited to race, age, language, geography, gender identity, sexual orientation and socioeconomic status. In this report, barriers and needs are presented by community. It is important to recognize that diversity exists within each community. Further it is critical to note that there are intersectional barriers and needs among communities. Although the intersectionality of barriers and needs among communities are not outlined in this report, this lens should be applied when providing information, support and practical services. Lastly, to provide effective supportive care, organizations and the healthcare system need to work collaboratively to provide person-centred cancer care.

At the Canadian Cancer Society, the evidence gathered through the underserved communities project summarized in this report will guide engagement efforts and strategies to better serve communities that are underserved with our information, support and practical services in a meaningful, evidence-informed way. These roadmaps have been the foundation to guide CCS with supporting underserved communities since 2019. Subsequent work has engaged with people from underserved communities to understand more about the barriers and opportunities identified in published literature and from other organizations. For the next phase of this work, we are embarking on activities to co-design solutions with people who have lived experience with cancer from communities that are underserved. To learn more about our ongoing work with underserved communities and commitment to reducing health inequalities, visit cancer.ca/HealthEquity.

Our commitment is to be an aspiring leader or ally guided by honesty, transparency, accountability, and our mission-guiding principles to support and develop services for underserved communities impacted by cancer. This report was developed to share key learnings that support communities that are underserved. We encourage other organizations to co-develop tailored initiatives for communities that are underserved, guided by the perspective of people from those underserved communities.

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