



Canadian
Cancer
Society



LIVING AT THE CROSSROADS OF COVID-19 AND CANCER

A what we heard report by the
Canadian Cancer Society

Introduction

The COVID-19 pandemic has disrupted all facets of cancer care across Canada and worldwide, with the long-term impacts on people facing cancer, their caregivers and healthcare providers yet to be fully realized. It has strained our health system and laid bare its many gaps and vulnerabilities. From delayed cancer screenings to suspended clinical trials, the fallout from pandemic disruptions may be felt by people in our health system for years to come.

Our government and healthcare leaders in Canada continue to make incredibly difficult decisions to ensure there is capacity nationwide to support those affected by COVID-19. Frontline healthcare workers are doing the best they can with limited resources and in a rapidly changing situation. Meanwhile, cancer has not stopped being a life-changing and life-threatening disease.

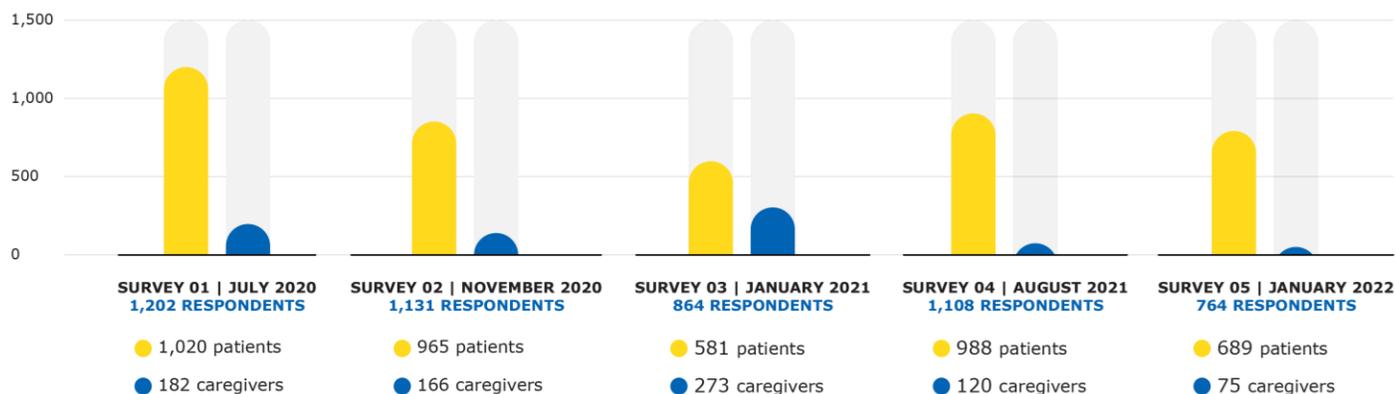
People with cancer are among the most vulnerable in our communities and may face a higher risk of more severe outcomes from COVID-19. Anxiety levels have increased and concerns from people with cancer and their caregivers about receiving appropriate care were documented time and time again through the pandemic. As the voice for Canadians who care about cancer, we are committed to telling their stories and fostering change.

This report documents the experiences of people facing cancer, their caregivers, and others caring for them through the pandemic and gathers their perspectives on the way forward. It portrays delays or disruptions in screening, diagnosis and cancer care over the past two years, along with some of the challenges our healthcare system will face moving forward. Guidance is offered to policymakers throughout Canada to better respond to the needs of all those impacted by cancer, both now and when the worst of the COVID-19 pandemic is finally behind us.

We've listened

Throughout the pandemic, the Canadian Cancer Society actively engaged with and listened to Canadians with cancer and their caregivers, providing us a unique sightline into the continued impacts of the pandemic on the cancer journey. We have drawn together insights and trends from our ongoing support programs, conducted 11 focus groups and three nationwide roundtables with healthcare and policy experts, healthcare providers, people with cancer and caregivers as part of a wider engagement effort, and deployed five nationwide surveys examining the effects of COVID-19 to understand how, and to what extent, the pandemic has impacted cancer journeys in Canada. We also supported a study conducted by McGill University aiming to identify the systemic factors that have shaped people with cancer and caregiver experiences through COVID-19 through three sources of Canadian Cancer Society collected data: qualitative free-text responses from 4,295 patient and caregiver surveys, data from 5,223 encounters with a cancer information helpline, and 540 entries made to a web-based community forum.¹

Surveys led by Canadian Cancer Society



STAKEHOLDERS

Leaders of community-based organizations and governmental agencies, primary care workers (nurses, family practitioners and specialists), CCS Board members and senior leadership, social workers, and other allied professionals.

Our ongoing engagement efforts allow us to tell the story of the more than one million Canadians living with and beyond cancer through this unprecedented time in our history. Too often, people impacted by cancer described how delays and postponed cancer care, and later eligibility for vaccines, led to this perception that there was a de-prioritization of cancer care as the pandemic took hold.¹ As we move forward, decision-makers must not be forced to choose between prioritizing the ongoing response to the pandemic or quality cancer care. To do so, our goal is to bring the experiences of people facing cancer to those decision-makers to foster a resilient, person-centred healthcare system that can withstand the pressures brought on by a pandemic.

Screening, Detection and Diagnosis During a Pandemic

Cancer screening and early detection services are essential components of the cancer control continuum, but the onset of the COVID-19 pandemic led to major disruptions of these programs across Canada. To make sure the health system had the ability to respond to a surge of COVID-19 patients, cancer agencies, cancer centres and hospitals took the unprecedented step of delaying and postponing cancer screening programs and diagnostics during the first wave of the pandemic. While organized cancer screening programs were largely resumed in the latter part of 2020, the effects of the sudden and initial delay, along with the backlog of some screening tests that persists, continues to be felt nationwide.

This initial delay introduced barriers that impacted access to screening and early detection services and, eventually, to diagnosis and treatment. In addition to system impacts, some individuals feared being exposed to the virus in a healthcare setting and did not want to burden the healthcare system.² Widespread delays in diagnostic pathways across Canada created additional delays, as demonstrated by Canadian healthcare access data and reports. These reports highlight widespread interruptions of cancer-screening programs and routine diagnostic procedures in Canada since the start of the pandemic.^{3,4,5}

The table below shows the impact of COVID-19 pandemic on cancer screening numbers in select provinces across Canada. The data shows the percentage decrease in cancer screening completed in March to December 2020, compared with the same time period in 2019.

Reduction in cancer screening ⁶

Cancer screening type	AB	BC	NB	NL	NS	ON	PE	QC
BREAST CANCER	▼ 68%	▼ 37%		▼ 39%	▼ 62%	▼ 53%	▼ 18%	▼ 37%
COLORECTAL CANCER	▼ 35%	▼ 13%	▼ 29%	▼ 25%	▼ 65%	▼ 56%	▼ 31%	▼ 30%
CERVICAL CANCER	▼ 26%	▼ 39%	▼ 28%	▼ 23%	▼ 35%	▼ 47%	▼ 76%	

Outcomes of delayed screening

Screening tests help find some types of cancer before a person has symptoms. Cancer that is found early is often easier to treat. Early detection can mean less demand on the healthcare system and less burden on those impacted, be physical, psychosocial or financial.

Using mathematical and various simulation models, researchers assessed the impact of provincial screening program interruptions for breast and colorectal cancer in Canada. For breast cancer screening, a six-month interruption could lead to about 670 additional advanced breast cancers and 250 additional breast cancer deaths. For colorectal cancer, a six-month delay in screening could increase colorectal cancer cases by about 2,200 with 960 more colorectal cancer deaths.⁷

Screening Delays Outcomes ⁷

BREAST CANCER INTERRUPTION 6-MONTH DELAY:	COLORECTAL CANCER INTERRUPTION 6-MONTH DELAY:
 <p>670 Additional late-stage diagnoses</p>	 <p>1,320 Additional late-stage diagnoses</p>
 <p>250 Additional deaths</p>	 <p>960 Additional deaths</p>
 <p>8,000 Additional life-years lost</p>	 <p>31,000 Additional life-years lost</p>



NEW PATIENT REFERRALS

Over 20% decrease in SK, ON and QC
10–20% reduction in MB



IN THE FIRST 6 MONTHS OF PANDEMIC IN CANADA

25% reduction in diagnostic imaging



IN 2020

Significant decrease in pathology reports, MRI scans and CT scans compared to the previous years.

DECREASE IN DIAGNOSIS

MB: 23% decrease in the number of new cancer diagnoses in April 2020.

AB has been public about having approximately 10–20% fewer cancer diagnoses during the pandemic.

QC estimates about 20% decrease between March and July 2020.

BC and ON estimate decreases of about 20% and 25%, respectively, in the first wave.

IN JANUARY 2022

15% of surveyed people with cancer reported experiencing delays in receiving their diagnosis – 13% of those who were diagnosed prior to the pandemic and 20% of those who were diagnosed during the pandemic.

Delays in screening, detection and diagnosis will impact Canadians for years to come, and the healthcare system will need to contend with a surge in cancer diagnoses now that screening services have resumed, many of which may be detected at an advanced stage. This surge of later-stage cancer cases may impact mortality and survival.¹³

MÉLODIE'S STORY

Mérodie was scheduled for a biopsy to determine whether the nodules on her thyroid were signs of cancer. But the day before her appointment, she got a call that so many others received. Her biopsy was cancelled, and she was left not knowing how long she would have to wait or if she was immunocompromised in the meantime. Mérodie's experience is not unusual. Throughout the pandemic, people affected by cancer across the country have faced similar challenges such as delayed diagnostic procedures and delayed surgeries.

"It's been three months since I saw the results of my scan, and it had taken them a year to notice the potential malignancy of the nodules on my thyroid. Am I going to have to wait another year to find out that it's worse than what it is? I'm petrified of finding out that my chances of survival are decreasing with the wait times for biopsies because of COVID-19. I'm scared, I'm very scared."

Mérodie is aware that the risk of late detection is concerning and can be detrimental – when cancer is found and treated early, the chances of successful treatment are better.

Changes people impacted by cancer want to see¹⁴

- ❖ Dedicated resources for organized cancer screening programs continue to operate safely and equitably during a pandemic, with a clear communications strategy for the public
- ❖ Screening operation plans should include tailored program activities to ensure equitable access and participation in screening services, especially for underserved communities
- ❖ Access to quality and timely screening and diagnostic services across provinces and territories, coast to coast to coast, urban to rural and remote

Charting a path forward

In the coming years, a surge of people throughout Canada will seek screening, detection and diagnostic services through a healthcare system that is not equipped to contend with sudden increases in demand. Studies show that resuming screening and detection services will not be enough; even with a return to the capacity seen before the pandemic, the healthcare system would not have the capacity to deal with the wave of cancer cases caused by a short-term disruption.⁷

Despite these challenges, decision-makers have an opportunity to reassess current programs and take decisive actions to address the surge the healthcare system may face. Most programs and facilities were already running at full capacity prior to the pandemic, with trained personnel in short supply in Canada. Investments are needed now to begin recruiting, hiring, and training personnel to contend with the surge in demand for cancer screening and diagnostics. Increasing access to equipment will also be necessary given the expected increase in the volume of diagnostic procedures that require the same imaging equipment and personnel usually assigned for screening purposes.

During our roundtables and focus groups, many stakeholders highlighted the need to apply lessons learned throughout the pandemic to innovate, strengthen and transform cancer screening. They called for a strong, immediate focus on prioritization strategies to triage urgent and priority cases to address the surge of diagnostic procedures without infringing on early detection and screening services. Some examples included leveraging stool tests to prioritize the use of colonoscopies, or repurposing information systems developed for the pandemic to gather screening prevalence data in various populations and jurisdictions to ensure responsive targeted cancer-control services.

Stakeholders also identified the need for a prioritization strategy addressing populations experiencing disparities in cancer screening. The pandemic has disproportionately impacted some communities and intensified some of the widespread health inequities that were already present and growing before 2020, especially disparities in cancer screening and detection. Loss of income and loss of housing have also been exacerbated by the pandemic, which in turn also affected early detection and screening access. Lower-income neighbourhoods and recent immigrants also have significantly lower rates of cancer screening.^{15,16,17,18}

Evidence demonstrates that Indigenous peoples, LGBTQ2+, racialized communities and women face inequities and barriers in accessing quality, timely and safe healthcare.^{19,20,21,22} Data collection and monitoring, tailored education, effective strategies to meet the needs of underserved communities, co-creation of services and programs, and support for community-based facilities to provide early detection and screening care closer to home were among the solutions identified by stakeholders through our engagement efforts. One example is tailoring

education and promotion of mammography to Métis women and First Nations women living on-reserve, given both populations have lower rates of breast cancer screening compared to non-Indigenous women.²³ Our roundtable and focus group participants reiterated the importance of having equitable, accessible and targeted screening services to ensure increased participation, especially for underserved communities. CCS will continue to prioritize engagement with underserved communities.

As we gradually move toward new phases of the pandemic, we have an unparalleled opportunity to reassess and adapt processes in place to regain lost ground and restructure cancer control systems to be resilient to extraordinary disruptions and responsive to the needs of all Canadians.

Disruptions and Quality of Cancer Care During a Pandemic

The pandemic brought challenges and distress to many people in Canada over the last two years, but people impacted by cancer faced significant hardships. In addition to the pandemic's financial, psychological and social challenges, their vulnerability to infections and limited access to caregivers and health services put them at additional risk of complications from both COVID-19 infections and disruptions of treatments. When we engaged with people with cancer and their caregivers, they reported higher levels of anxiety and concern about receiving appropriate cancer care. This was particularly the case for people with cancer during the first year of the pandemic, whereas caregivers consistently reported higher levels of anxiety and concern throughout the pandemic.²⁴ Both people with cancer and caregivers shared their stories of delays and interruptions in care, which were more common among cases diagnosed during the pandemic than cases diagnosed prior to the pandemic.²⁴

Surveyed people with cancer remained concerned about their physical health.²⁴ They indicated they are still anxious about the quality and success of their treatment as they face treatment interruptions or changes, delays in starting their treatment, cancelled or delayed surgeries, reductions in their number of treatments and lack of access to healthcare providers or equipment over the last two years.²⁴

People with cancer remain more vulnerable to COVID-19 infections and at higher risk of serious outcomes compared to those without cancer, making decisions around goals of care much more complex. They need to navigate a health system already stretched thin while trying to gain a basic understanding of their treatment options and balancing the benefits and potential risks of treatments during the pandemic.

Since the beginning of the pandemic, caregivers provided, and continue to provide, more support than usual, which they say has led to greater levels of distress. Despite this increased level of care, their inability to accompany their loved ones to cancer treatments or appointments due to pandemic restrictions has consistently been the most reported disruption. Although both caregivers and people with cancer are concerned with catching COVID-19, caregivers generally reported higher levels of concern.

Concerns of Caregivers and People with Cancer²⁴

Percentage of caregivers reported being concerned about their loved one being able to

76%

Get help if they experience side effects or new symptoms related to their treatment

54%

Receive timely care or treatment

60%

Get appointment with physicians or healthcare providers

41%

Get medicines to treat or manage cancer

57%

Access mental health or psychosocial supports



76% OF CAREGIVERS

reported feeling 'rather anxious' or 'very anxious'.



36% OF PEOPLE WITH CANCER

reported feeling 'rather anxious' or 'very anxious' during the pandemic.



45% OF CAREGIVERS

indicated they provided more care than usual.

Compared to people with cancer, caregivers reported greater levels of concern related to catching COVID-19 (77% vs. 67%), their physical health (77% vs. 67%), their physical health (62% vs. 60%), and employment (45% vs. 18%).

ALEXIS'S STORY

After giving birth to her youngest daughter in July 2019, Alexis was shocked and surprised to be diagnosed with colon cancer only nine months later, at the age of 35. As a healthcare worker and active mother to three young children, Alexis began her cancer journey in spring 2020, after she noticed traces of blood in her stool. Due to the COVID-19 pandemic, she experienced delays in determining the stage of her cancer diagnosis and her friends and family were not able to offer help in-person.

"It felt very strange starting off my cancer journey in 2020, since the pandemic brought about new challenges. Because of the impacts of COVID-19, no one was allowed in the hospital with me for my initial colonoscopy or during my surgery, and even after surgery no one could come into the hospital to visit. Not having my family physically with me definitely made my experience more difficult."

Caregivers play a vital role in cancer care, acting as a support system for their loved one's living with cancer, but they are often undervalued and overworked. Caregivers want and deserve access to the supports needed to help them so they can continue to help their loved ones through their cancer journey.

Research and clinical trials were also impacted across Canada. While some clinical trials remained open, patient accrual was suspended in Manitoba, Québec and Newfoundland and Labrador.³ To decrease the risk of COVID-19 infection, many research facilities limited staff presence in labs and stopped enrollment and activities such as blood and other tissue collection. Funding gaps and decreased donations to philanthropic organizations also impacted research and clinical trials.²⁵

Outcomes of treatment disruptions

There was a significant decrease in pathology reports, MRI scans and CT scans in 2020 compared to the previous years.^{5,26} These delayed diagnoses may present with more advanced cancer stages and require more complicated treatment and care, putting added pressures on an already strained oncology workforce.²⁷ Even before the pandemic, the Canadian Cancer Statistics Advisory Committee had anticipated a significant increase in cancer cases between 2028 and 2032 compared to 2003 and 2007 as a result of the growing and aging population, calling for optimization and expansion of cancer care capacity.²⁸ The adverse effects of the pandemic on the provision of cancer care will only exacerbate the already precarious state of cancer care across Canada.²⁹

Disruption experience of people with cancer and caregivers during the pandemic^{2,24}

In January 2021	The 5 most frequently reported disruptions by patients in January 2021 are:	The 5 most frequently reported disruptions by patients in January 2022 are:
<p>52% of respondents with cancer reported they experienced a disruption, of which 22% say it worsened their confidence in their care, with feeling a lack of control often cited as a reason for worsened confidence</p> <p>Of people with cancer who remain confident in their care, 53% indicate that open and transparent communication is crucial to managing the impacts of disruptions to care and maintain levels of confidence</p> <p>82% of caregivers saw their loved one experience disruptions in care, 40% of which indicate it worsened their confidence</p> <p>46% of patients say reducing exposure to COVID-19 is a significant concern when discussing treatment with their physicians</p>	<ol style="list-style-type: none"> 1. My caregiver was unable to accompany me to a cancer treatment or appointment due to restrictions 2. The doctor managing my cancer care cancelled or postponed my in-person appointment 3. My treatment was changed, e.g. a different dose of medicine or chemotherapy or a switch to a different type of medicine 4. I had trouble contacting my doctor, healthcare provider or cancer care team to get information 5. I avoided going to the hospital emergency room for symptoms related to my cancer 	<ol style="list-style-type: none"> 1. My caregiver was unable to accompany me to a cancer treatment or appointment due to restrictions 2. The doctor managing my cancer care cancelled or postponed my in-person appointment 3. I had trouble contacting my doctor, healthcare provider or cancer care team to get information 4. I avoided going to the hospital emergency room for symptoms related to my cancer 5. I avoided going to see my family doctor for symptoms related to my cancer

ISABELLE'S STORY

Isabelle, a mother and young grandmother, had already been through treatment for bladder cancer in 2018 when she was told in 2019 that she may have cancer again, this time in her lungs. After several scans, her surgeon recommended surgery to remove a nodule on her lungs that he feared was cancerous. By then, the hospital system had been turned upside down with the arrival of COVID-19, which was going to force the postponement of tens of thousands of surgeries throughout the country, increasing Isabelle's anxiety tenfold.

"I called regularly. I was worried. I asked if it was getting bigger and if it was going to get worse."

It was a very stressful time for Isabelle, who was put on medical leave by her doctor. After months of waiting anxiously, Isabelle finally had the nodule on her lung removed, which turned out to be cancerous.

"I'm glad I did the surgery because it did turn out to be lung cancer that was caught early."

People with recently diagnosed cancer are concerned with how their treatment will be impacted by the pandemic. The potential of late-stage cancer can put significant strain on the individual and caregivers' mental health, and the lack of knowledge about what can happen if they wait too long places an undue burden on people with cancer.

During the first six months of the pandemic, there was a 20% reduction in cancer surgeries across Canada. Through mathematical models and real-world data analysis, researchers estimated the devastating strain put on our healthcare system by the pandemic will lead to a significant increase in cancer-related deaths over the next decade. Specifically they estimate an additional 21,247 cancer-related deaths in Canada between 2020 and 2030.⁸ Looking at the compounding effects of screening, diagnostic and treatment delays and disruptions, some models predict that a 10% increase in cancer diagnostic and treatment capacity would mitigate a significant number of the excess mortality.⁸

Outcome of Treatment Capacity⁸

Keeping capacity for cancer treatment 10% lower than normal throughout 2021 will lead to 33,262 excess cancer deaths between 2020-2030.

Increasing treatment capacity by 10% over normal beginning June 2021 will lead to 4,210 excess cancer deaths between 2020-2030 – such an increased capacity would prevent approximately 80% of the estimated excess cancer mortality.

Charting a Path Forward

Stakeholders and healthcare providers we engaged indicated the challenges currently experienced cannot be solved by simply injecting more money into the current healthcare system; new models of care, a focus on equity, research, and investment in capacity and infrastructures are required to give people with cancer the care they deserve.

Alternative models of care, such as leveraging virtual care, offering patient navigators and optimizing the role of nurses and social workers in outpatient cancer settings, can help healthcare providers address challenges and barriers brought on by the pandemic and offer accessible, effective and safe cancer care. In our survey, 79% of respondents with cancer reported having had virtual healthcare appointments, although 44% rated the quality of virtual appointments worse than in-person appointments, 63% would likely accept a virtual healthcare appointment beyond the pandemic.² However, people with cancer and caregivers shared that good communication and the ability to ask questions were key to feeling like virtual appointments were the same or better than in-person appointments. Survey results revealed people with cancer and caregivers want increased opportunities to communicate with their healthcare teams, with 39% of people with cancer and 37% of caregivers saying they must have the ability to ask questions related to treatment.²⁴

Providing access to cancer care that is responsive to the specific needs of people of all ages and socio-economic and cultural backgrounds is key to addressing the numerous gaps in cancer care across Canada. Investing in rural and remote community health centres and in underserved communities is necessary to ensure care can be delivered to all Canadians. While a comprehensive, nationwide approach to cancer care planning is highlighted as a priority by many stakeholders, so is the development of innovative models of care that ensure Canadians can access healthcare services where they live. The socio-economic impacts of the pandemic and how it affected cancer care varies across provinces and territories, highlighting the necessity of tailored solutions to address the needs of people with cancer across Canada. For example, our survey highlighted significant differences among provinces around the number of respondents who indicated the doctor managing their cancer care had to cancel or postpone in-person appointments, or respondents who reported they had trouble contacting their doctor, healthcare provider or cancer care team to get information.² There were also notable differences among provinces around the number of caregivers who reported they were unable to accompany their loved ones to a cancer treatment or appointment due to COVID-19 restrictions.²

Through our engagement activities, the majority of stakeholders agreed that accessible, responsive cancer care across Canada cannot happen without significant investments in healthcare capacity and infrastructures. While short delays in cancer treatment and surgery may not have a significant impact in most cases, longer delays may impact survival of people with cancer³⁰. Increasing the capacity of our healthcare system to address the upcoming surge in cancer cases will be paramount to maintain adequate cancer care. The pandemic has strained healthcare workers, which can further jeopardize the quality of our healthcare system; healthcare providers remain a key ally for people with cancer through their cancer journey, who need to count on a healthy oncology workforce.

Changes people with cancer, caregivers and healthcare providers want to see¹⁴

- ❖ Ensure sufficient health human resources (e.g., nurses, technologists, social workers) to meet needs, protect healthcare, and create a safe, robust and healthy workforce.
- ❖ Develop a plan to clear the procedural backlogs
- ❖ Explore the role of healthcare navigators to guide people with cancer and caregivers in their cancer journeys
- ❖ Ensure diverse voices of people with cancer and their caregivers are included when making decisions around health care delivery
- ❖ Support people with cancer as they transition from the cancer care system into recovery and survivorship
- ❖ Establish policies to recognize the importance of caregivers in the care process and as an essential part of the healthcare team
- ❖ Ensure psychosocial supports are available to people with cancer and caregivers
- ❖ Guarantee availability of and accessibility to timely and appropriate palliative care and end-of-life care

Information and Psychosocial Supports

Beyond disruptions to and reallocation of medical resources, people with cancer also have to contend with having less access to many resources that support them in their cancer journey. These resources, such as patient support groups, cancer wellness centres, assistive equipment, nutrition counseling, tailored yoga sessions, rehabilitation services and physical therapy, are essential in supporting the mental health, pain management, safety and physical wellbeing of people with cancer.^{31,32} Various researchers examined the impact of the pandemic on the mental health and wellbeing of people with cancer and found they significantly reported feelings of being “abandoned” or “forgotten,” suffered from isolation and experienced increased difficulties in managing their pain.^{31,32} Nearly 67% indicated they were anxious or experienced worsening of existing mental health difficulties because of the pandemic, 30% could not maintain a healthy lifestyle, and 63% reported higher than usual stress.^{31,32} Caregivers reported similar mental health challenges, with more than three quarters of respondents indicating they felt anxious during the first year of the pandemic.²

MÉLINA'S STORY

Young, athletic, and competitive by nature, Mélina was 26 years old and 27 weeks pregnant when she was diagnosed with the most aggressive form of breast cancer. The COVID-19 pandemic forced her to combine treatments to avoid hospital visits, so her chemotherapy was administered in large doses, which left her feeling physically and mentally weak. Going through intensive treatment with a newborn baby was crushing and left her in desperate need of support.

“My bones hurt and I was bedridden. It was unbearable. I couldn't even take care of my baby anymore. It was a heartbreaking situation, but I had to keep going for my child. After nine months of debilitating treatments and rounds of chemotherapy, hair loss, muscle mass loss, radiotherapy and a partial mastectomy, my soul was crushed and I needed help to regain my will to live.”

Emotional support is essential for people with cancer and their loved ones. A cancer diagnosis can change everything – it can leave people feeling alone and scared as they face a new challenge that will require strength, courage and hope. Resources for psychological support are an important comfort to people going through the cancer journey. Making them more accessible is an important investment in overall cancer care.

Palliative care

The COVID-19 pandemic has also impacted the access to and delivery of palliative care. Of the respondents who were caring for people with cancer who required palliative care, over a third indicated their loved ones experienced challenges in receiving palliative care, which included pain and symptoms management, psychosocial, emotional and spiritual support, and comfortable living conditions with the appropriate level of care.² There are many issues people with cancer and their caregivers need to attend to during their cancer experience or at end-of-life, such as pain management, anxiety and depression, grief and bereavement, and advance cancer planning to name a few. However, the pandemic put a strain on palliative care resources, which limited access for people with cancer at a time they needed them the most. Person-centred palliative care is essential across a broad range of care settings for the wellbeing of people with cancer and their caregivers. Such care addresses their physical, emotional, spiritual and pain management needs, improves quality of life and increases efficient use of healthcare resources.³³ Even before the pandemic, access to palliative care varied across provinces and territories and was particularly limited for rural and remote communities and Indigenous populations.³⁴ Furthermore, some palliative care medications were unavailable during pandemic surges.³⁵ Isolation protocols and the shift to virtual care during the COVID-19 pandemic created additional hardships for those facing homelessness, those in rural and remote communities, and Indigenous peoples to access high quality palliative care.³⁶

The COVID-19 pandemic magnified the demand for grief and bereavement support and spiritual care resources. Virtual grief supports and resources were instrumental in addressing both caregiver and staff needs. Given the losses endured in the pandemic, there is a pressing need for these supports to be enhanced and sustained. Advanced care planning and goals of care discussions became imperative during this period. Adoption of new and existing tools and resources provided an opportunity to better address the wishes of people with cancer during this period of crisis but also highlighted the additional work is required to streamline communication across healthcare settings and incorporate virtual technologies into these sensitive discussions.

The pandemic also amplified the importance of timely access to palliative care education and training for community healthcare providers. The ability of national, regional and local organizations to provide widespread, virtual palliative care education, tailored to needs of diverse healthcare provider groups, was instrumental in building the skills and capacity of primary care and community clinicians to deliver high quality palliative care. Working to full scope of practice became both a necessity and an opportunity during acute staffing shortages. The pandemic further served as an impetus for teams to come together to reorient roles and strengthen interprofessional collaboration in order to improve people with cancer and caregiver experience.

Beyond Clinical: Financial burden of cancer

The financial strain experienced by people with cancer and their caregivers was significant before the pandemic and was exacerbated by it, especially in underserved populations. A systematic review of the literature from 2006 to 2020 (i.e., before the pandemic) demonstrated that certain groups carried a significant financial burden related to cancer care. The literature review shows that women, people living in remote or rural communities, young Canadians, the self-employed and caregivers of children with cancer all with higher indirect cancer care costs.^{37,38} Caregivers in general faced costs ranging from \$15,786 to \$20,414 per patient per year. In addition to decreased revenue caused by loss of employment or reduced hours, common out-of-pocket costs assumed by people with cancer and their caregivers include:

- ❖ Prescription drugs
- ❖ Lack or loss of private insurance due to loss of employment
- ❖ Accommodation, travel, meals, and parking for treatments
- ❖ Devices and equipment
- ❖ In-home healthcare and homemaking services
- ❖ Complementary and alternative medicine, such as medicated mouthwash, vitamins and supplements to deal with treatment side effects
- ❖ Family care and childcare

When asked to rank the supports they need to manage care, people with cancer and caregivers most commonly selected “access to drugs and prescriptions,” “financial supports” and “ability to ask questions” as the most important during the first year of the pandemic.^{2,24} During the second year of the pandemic, “financial supports” and “access to drugs and prescriptions” remained the most common supports selected by caregivers.² In January 2021, approximately 3 in 5 people with cancer reported having access to various supports to cover the cost of cancer treatments.²⁴ The use of financial programs and supports, such as the Canadian Pension Plan (CPP) and private insurance, by people with cancer and their caregivers remained about the same through the first year of the pandemic, with 1 in 5 people with cancer and caregivers accessing CPP. However, about 40% of respondents with cancer have not accessed any financial programs or supports.²⁴ People with cancer and their caregivers can have significant out-of-pocket costs and loss of revenue due to time spent traveling to and from health care, waiting for care, and receiving care, making financial support critical for many of them.

For people living with cancer and caregivers living in rural and remote areas, additional costs for healthcare come into play. When asked to rank resources and supports most needed, both rural and urban respondents ranked access to drugs and prescriptions first (84% and 79%, respectively), while only rural respondents included financial support from the government in their top three most needed supports (73%).²⁴ People living with cancer in a rural setting are also less likely to access provincial drug programs (28%) and private insurance (28%) compared to those living in an urban setting (33% and 31% respectively).²⁴

DON AND LEE'S STORY

For Don, the journey from his home in Pemberton, British Columbia to Vancouver for six-and-a-half weeks of radiation treatment was difficult enough before his plans were made even harder with the added complication of the COVID-19 pandemic. Along with the complications of navigating treatment while hospitals and cancer centers struggled under COVID-19, Don and his wife Lee also had to consider the challenges of receiving treatment so far from home.

"We were quite concerned because we live far from Vancouver, it's about a two-hour drive, an extra half-hour to the hospital. There's also the cost of hotels and everything. Although my doctor recommended the treatment, I was cautious because of COVID-19 and how we were going to remain safe during the daily visits to the treatment facility."

Virtual care is not always an option available in remote and rural communities. People with cancer and caregivers want decision makers to explore policy directions that will offer more care closer to home and provide financial supports to offset the additional costs associated with cancer care away from home.

Conclusion

Cancer diagnosis is already a profoundly stressful life event, but it has become even more overwhelming during a pandemic. From being at increased risk for more severe outcomes from COVID-19 to social isolation and anxiety related to delays or disruptions in treatment, people living with cancer remain among the most vulnerable in our communities. Their safety, as well as the safety of their caregivers and the many healthcare providers supporting them in their journey, must be a priority.

The Canadian Cancer Society continues to leverage its resources and partner with people impacted by cancer to learn how the pandemic has affected and continues to affect each stage of the cancer journey. Despite the challenges that remain, policy makers across Canada have an opportunity to draw on these experiences and enact positive change to support all those impacted by cancer. We call on policy and decision makers to make the healthcare system better by drawing from the lived experiences and evidence presented in this report, a system capable to respond to the needs of all those impacted by cancer.

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