

LYMPHOMA
CANADA



LYMPHOMA CANADA COVID-19 REPORT

Lymphoma and CLL Patient and Caregiver Experience

Results from the 2020 and 2021 Lymphoma Canada Surveys



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This report will summarize the Canadian lymphoma and chronic lymphocytic leukemia (CLL) patient and caregiver experience related to the COVID-19 pandemic. It will highlight the health impacts of the virus, vaccine administration and experience, impacts and disruptions to healthcare and quality of life, and expectations for improving outcomes impacted by the pandemic for the lymphoma and CLL community.

Lymphoma Canada is a registered charity and Canada's only national organization focused entirely on lymphoma. Lymphoma Canada connects and empowers the lymphoma and CLL community. Together we are promoting early detection, finding new and better treatments, helping patients access those treatments, learning lymphoma's causes, and finding a cure.

Our Mission: Empowering patients and the lymphoma community through education, support, advocacy and research.

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Introduction

Lymphoma Canada has developed a fulsome report that provides valuable insight on the Canadian lymphoma and CLL patient and caregiver experience throughout the COVID-19 pandemic, providing 16 months of valuable feedback from experience surveys. The information collected and presented in this report includes key findings on the needs and challenges this community has faced throughout this pandemic, with the hopes that collaborative efforts will be undertaken to develop programs and services that will address their needs related to education, support, advocacy and research.

OVERVIEW OF THE COVID-19 PANDEMIC

The coronavirus SARS-Cov-2, designated as COVID-19 by the World Health Organization (WHO) on February 11, 2020, was initially discovered in Wuhan, China in December 2019¹. Coronaviruses are a class of viruses; different strains that have affected the human population include the SARS (severe acute respiratory syndrome) and MERS (middle east respiratory syndrome) coronaviruses². Most individuals infected with the COVID-19 virus will experience mild to moderate respiratory illness, and individuals can recover without treatment³. However, there are certain risk factors such as age, underlying medical conditions, and/or cancer, that increase the severity and impact, as well as the mortality risk, of this respiratory illness.

Due to the rapid human-human transmission of the COVID-19 virus, it had quickly become a health emergency of global concern. Endeavours were undertaken to reduce transmission which included societal closures and reduced capacity in indoor settings, physical and social distancing, the use of personal protective equipment (PPE), and increased hygienic practices (i.e. hand washing, sanitization). As of December 2021, there have been more than 270 million reported cases globally with over 5 million deaths⁴. In Canada, there have been 1.8 million COVID-19 positive cases with just under 30,000 deaths⁵. Cases and mortality rates had been on an alarming rise and without an end in sight, until the introduction of the COVID-19 vaccines in December 2020. Mass vaccination has had a substantial impact on mitigating COVID-19 outbreaks, reducing adverse outcomes and illness experience, and preventing hospitalizations⁶. To date, 8.3 billion vaccine doses have been administered globally, with 76% of the Canadian population being fully vaccinated (data collected on December 16, 2021)^{4,5}. Equitable access to safe and effective vaccines is critical to ending the COVID-19 pandemic⁷. However, for the foreseeable future, as we learn more about the long-term effectiveness of the vaccines, continued protective methods must still be practiced.

IMPACTS OF THE COVID-19 PANDEMIC ON CANCER PATIENTS AND CARE

Cancer patients are more vulnerable to contracting the COVID-19 virus and may experience more severe complications compared to the general population⁸. Depending on the type of cancer, patients may be mildly to severely immunocompromised, with certain cancer treatments (i.e. targeted therapy, immunotherapy) further decreasing the function and response of their immune system. Further, the impact of COVID-19 is greater for patients with certain types of cancer, such as in those with hematological malignancies like lymphoma and chronic lymphocytic leukemia (CLL). There have been a number of research studies published that indicate hematologic (blood cancer) patients in particular experience more complications, morbidities and higher mortality rates when contracting the COVID-19 virus compared to the general population⁹⁻¹³. Due to the increased risk for this cancer group, certain health measures have been implemented to protect this patient population. These methods include transitioning from intravenous to oral therapies where applicable, and virtual appointments with healthcare teams to limit interaction with potential COVID-19 infected individuals through the hospital setting, as well as priority access for the vaccines. As observed, cancer care has been profoundly impacted by the COVID-19 global pandemic. The different methods implemented such as prioritizing treatment based on urgency, modification of cancer therapy (dose delay, home care, oral regimens, extended intervals between cycles, etc.) and temporary closing of clinical trials, walk a fine line of trying to provide the best possible care for cancer patients while minimizing the risk of contracting the COVID-19 virus. Not only are cancer patients facing treatment impacts, but psychosocial aspects have received equal attention. Depression is the most prevalent emotional detriment among patients with hematological malignancies, decreasing patients' quality of life and cognitive functioning¹⁴. Among lymphoma outpatients in particular, high levels of anxiety (36%) and depression (31%) were recorded during the pandemic¹⁵. The impacts of these negative emotional consequences further complicate a patient's cancer experience during the pandemic; supportive care services are more important now than ever.

UNDERSTANDING THE NEEDS OF LYMPHOMA AND CLL PATIENTS

Hematologic (blood cancer) patients are a unique group of cancer patients that require specialized attention and continued care throughout the COVID-19 pandemic. This is due to the nature of the disease. Treatments for example are long, aggressive and requires ongoing maintenance compared to those with solid cancers¹⁶. Further, the immunosuppressive effect of certain treatments require patients to self-isolate for their own protection. The challenges and unmet needs faced by this patient population have been illuminated throughout the pandemic. Some of these challenges have included difficulties in accessing treatment, lack of consistent follow-up care or management, increased isolation and mental health impacts, and reduced availability of support services. **It is important that the challenges associated with managing patients with hematologic malignancies (blood cancers) during the COVID-19 pandemic are identified and actions are taken.**

To gather insight on the Canadian patient and caregiver experience throughout the COVID-19 pandemic, Lymphoma Canada developed two experience surveys that were administered to the Canadian patient and caregiver lymphoma and CLL community. The responses received from these surveys illuminate the lymphoma and CLL experience throughout the pandemic, highlighting the needs and challenges of this community in order to develop appropriate programming and services and advocate for change on a national frontier.

Methodology

The first Lymphoma Canada experience survey was developed and released in May 2020 and remained available until August 2020, offering insights into the patient experience at the beginning of the pandemic.

A total of 174 patients from across Canada provided feedback.

The second Lymphoma Canada experience survey was developed and released in April 2021, offering comparative feedback approximately one year from the start of the pandemic and lockdown procedures. This survey closed in August 2021. **A total of 198 patients and 12 caregivers from across Canada provided feedback.**

The lymphoma patient and caregiver responses to these surveys have provided insight in the following areas:

- impacts to clinical care and practice,
- psychosocial impacts, and
- the programs and services patients and caregivers are in need of.

Comparisons will be made between the experiences reported in the two surveys to see how these have changed over the course of the pandemic.

Major challenges for lymphoma and CLL patients and caregivers will be identified and summarised, and recommendations to patient organizations, policymakers, and other stakeholders in healthcare will be provided to improve the patient and caregiver experience.

Patient Experience

Lymphoma and CLL Canadian Patient Experience during the COVID-19 Pandemic



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HEALTHCARE EXPERIENCE AND SELF-PROTECTION DURING THE COVID-19 PANDEMIC

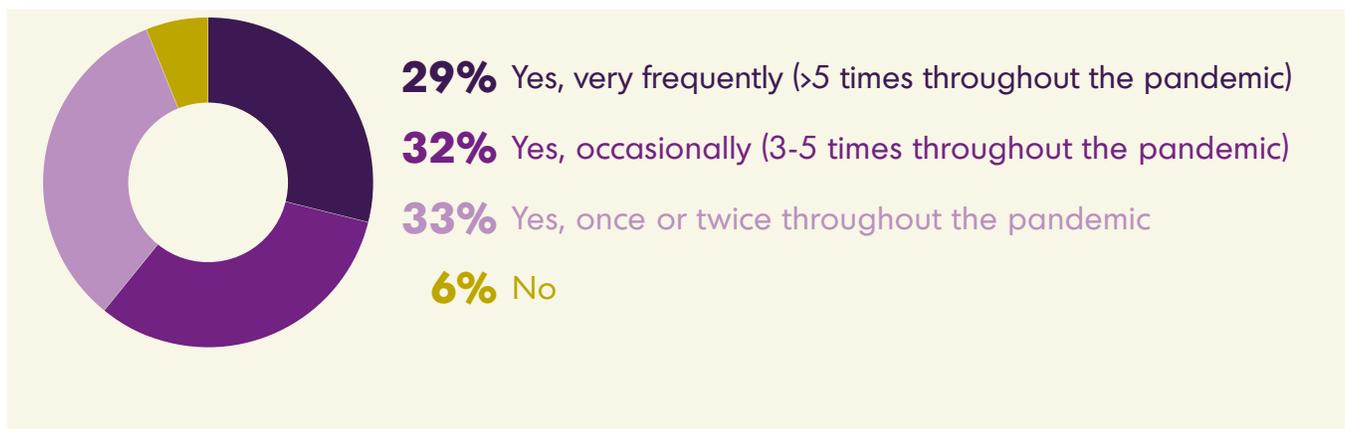
At the beginning of the pandemic, the impacts to healthcare for cancer patients were astounding with hospitals canceling non-emergent appointments, clinical trials coming to a standstill, and increased confusion with challenging policies that made it difficult for patients to receive treatment without increasing their risks associated with in-person hospital visits. Though these impacts were observed across nearly all cancer populations, **the majority of lymphoma and CLL patients (81%) responding to the Lymphoma Canada experience survey reported that they did not experience any delays in their healthcare at the beginning of the pandemic in April 2020 (171 respondents)**. Further, the majority of patients (74%) did not experience any changes to their treatment regimen, such as switching to an oral therapy or reducing their number of treatment cycles, and did not feel that the pandemic impacted their quality of care. This continues to be the experience even one year out from the start of the pandemic, whereby the most recent Lymphoma Canada experience survey found that 81% of patients felt they were still receiving the best care for their lymphoma and CLL (198 respondents). The majority of patients (59%) did not experience medicine shortages or difficulties in accessing certain treatments because of the pandemic; 36% were not on active treatment or did not require treatment during the pandemic.

“Some of my medication was rationed, initially, but that no longer is the case.”
– Anonymous Patient

Experience with Healthcare

Across Canada, different institutions adopted the use of virtual appointments if in-hospital treatment was not required in order to limit the potential exposure of their patients to the COVID-19 virus. With these new changes to healthcare appointments, the majority of lymphoma and CLL patients (90%) did not find it difficult to speak with their healthcare team throughout the pandemic (198 respondents). Patients provided further details on the frequency of their communication with their healthcare team throughout the pandemic (Figure 1).

Figure 1. Frequency of communication with healthcare team during the pandemic (198 respondents)



The majority of lymphoma and CLL patients had their appointments changed to a virtual setting as a result of the pandemic (198 respondents). Only 12% of patients continued with in-person appointments, while 39% had a mixture of in-person and virtual appointments. For those with virtual appointments, many had their appointments through telephone only (70 respondents), while only 8 patients had a combination of telephone and video appointments. This is similar to what was observed at the beginning of the pandemic, whereby the majority of patients had their virtual appointment through phone only (112 respondents), with only a few individuals being able to speak with their healthcare team through a video call (20 respondents).

“Scheduled office visits (last 2) were done by telephone. My healthcare provider was readily available if required.”

– Anonymous Patient

As clinicians obtain important information on a patient’s health status through observation and physical assessment, communication just by telephone may not have the same level of discussion and evaluation that a video call or in-person appointment would have. A number of patients reported that they prefer to have in-person appointments to ensure physical examinations are being performed to monitor lymph nodes and overall health.

“A 2-minute phone call is not the same as a physical visit with discussion of symptoms and palpation of areas of concern.” – Anonymous Patient

“No physical exam which is important for my mental health as well as checking my lymph node involvement.” – Anonymous Patient

Though the majority of patients (61%) indicated that the pandemic has not negatively impacted their cancer care (12% of whom were not receiving cancer care (survivor)), there is still a proportion of lymphoma and CLL patients that did experience impacts to their medical care (198 respondents). Most of these impacts were related to treatment and follow-up care. **Approximately 22% of patients found their follow-up care, including monitoring tests and procedures, to be negatively impacted by the pandemic through either cancellation, decreased frequency, or lack of communication on testing results.**

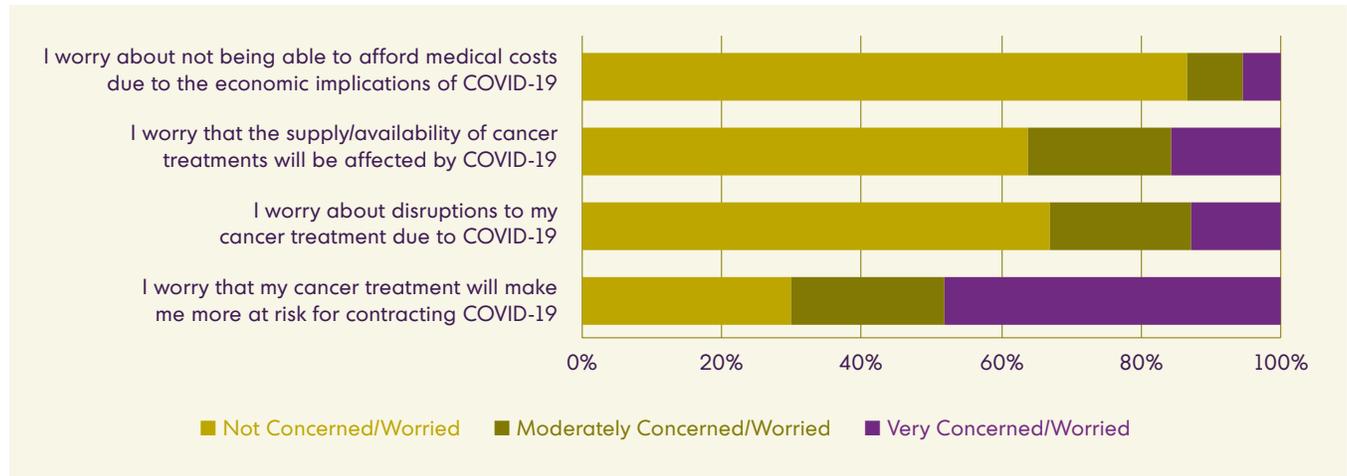
Approximately 16% of patients indicated access challenges with treatment options or even challenges in continuing on their current treatment plan. For those that did experience changes to their treatment plan, this involved surgery delays (3 patients), reduced treatment length (i.e. number of cycles) or delay in starting treatment (10 patients), stopped or delayed maintenance therapy (4 patients), or personally chose Watch and Wait (1 patient). Decisions that contributed to changes in a patient’s treatment plan included:

- Concerns about receiving treatment with a weakened immune system (i.e. increased risk of contracting COVID-19)
- Concerns about COVID-19 exposure risk with going into the hospital/clinic for treatment
- Hospital/clinic rules related to COVID-19 (i.e. visitor restriction)
- Transportation or travel concerns

“Because my immune system was very low before treatment started, my oncologist decided that I would receive only half the dose of my chemotherapy treatment.” – Anonymous Patient

Patients are also concerned about a number of important health impacts that may be caused by the COVID-19 pandemic (Figure 2). **Most patients were worried or concerned about their cancer treatments increasing their risk of contracting the virus, as they are likely to be further immunocompromised due to specific lymphoma and CLL treatments they may receive.**

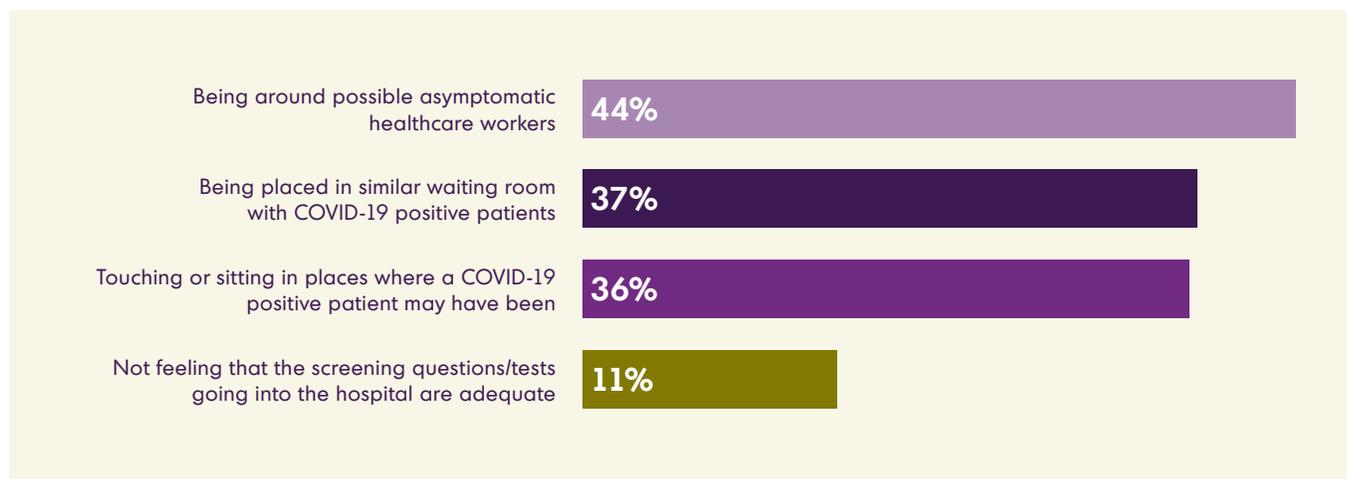
Figure 2. Patient’s healthcare concerns related to the COVID-19 pandemic (198 respondents)



Personal Care and Health

Throughout the pandemic, cancer patients have had to work even more closely with their healthcare team to make important decisions related to their health and care. The majority of lymphoma patients feel at risk going to the hospital or doctor’s office during the pandemic (62%; 198 respondents). **Of greatest concern was the risk of possible exposure to asymptomatic healthcare workers** (Figure 3). As a result of this fear, a number of patients, though small (13 patients), did not go to the emergency room (ER) for a concerning health problem that they normally would have gone to the ER for prior to the pandemic. **Fear of contracting COVID-19 and its impacts on immunocompromised patients has clearly impacted patient reporting of healthcare concerns and accessing much-needed healthcare.**

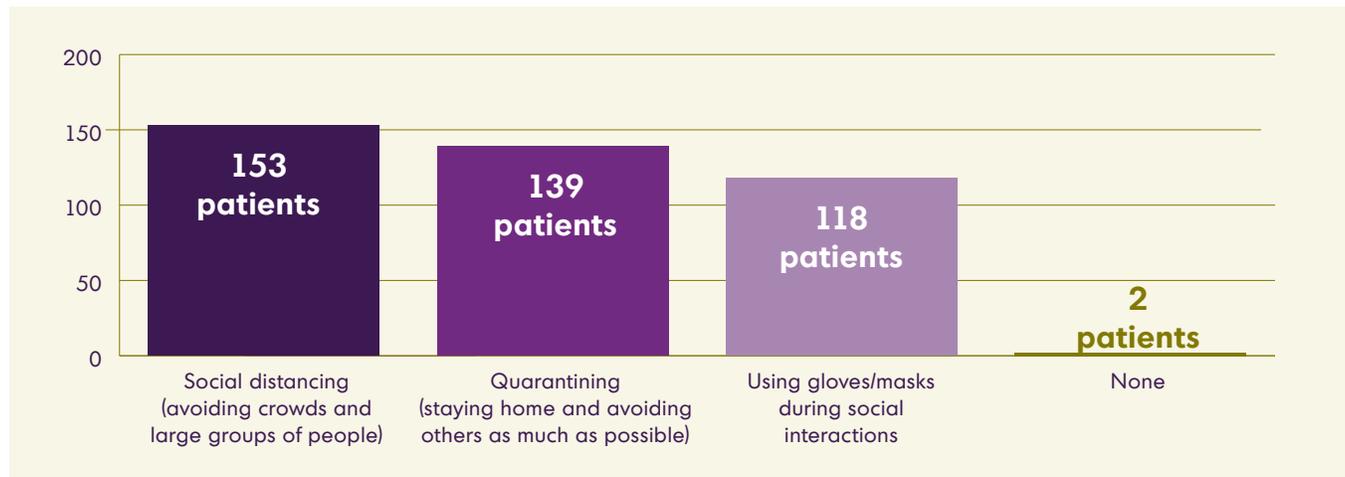
Figure 3. Patients’ concerns with in-person healthcare visits (198 respondents)



Lymphoma and CLL patients have worked exceptionally hard to protect themselves from the COVID-19 virus, and these efforts have continued throughout the pandemic. At the beginning of the pandemic, patients utilized a number of methods to protect themselves including social distancing, quarantining and using personal protection equipment (Figure 4).

**“Hand washing, sanitizing.
Having others grocery shop
for me as much as possible.”**
– Anonymous Patient

Figure 4. Methods of self-protection by lymphoma and CLL patients (172 respondents)

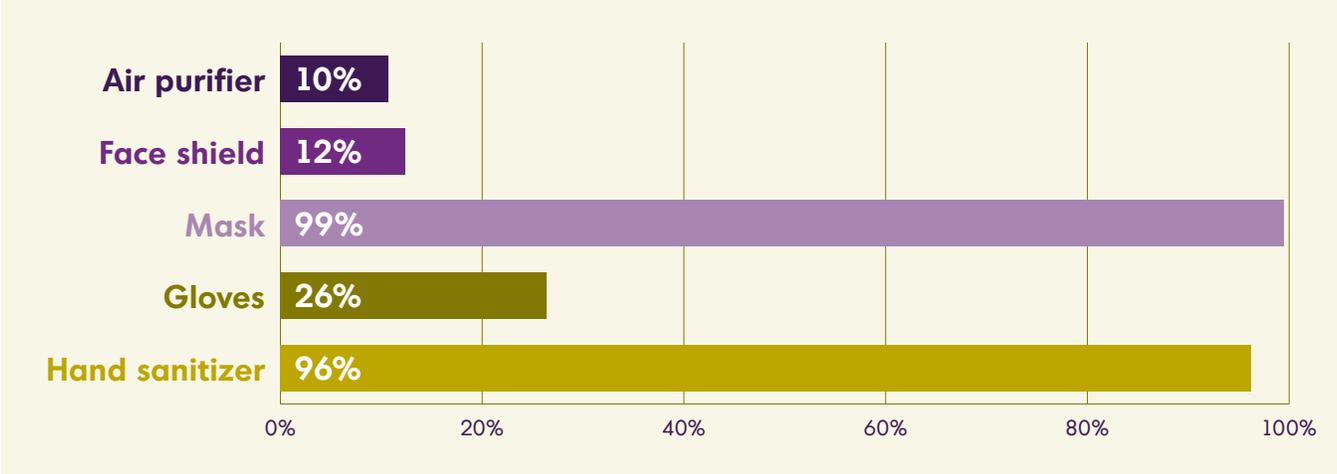


Even more than one year later from the start of the pandemic, and with increased vaccination rates of the general population, the majority of lymphoma and CLL patients are still practicing a number of safety methods to protect themselves from contracting the virus. This is important as even with vaccination, lymphoma and CLL patients have a reduced immune response compared to healthy individuals, and even other cancer patients¹⁷⁻²¹. Many patients (186 respondents) are still quarantining and social distancing by:

- Not seeing their family/friends in person (both in indoor and outdoor settings) (39%)
- Only seeing their friends/family in outdoor settings (48%)
- Not going to in-person congregations (grocery store, restaurants, shops, etc.) and only ordering online (34%)

In addition to vaccination for self-protection, patients have also continually used PPE. Patients indicated their perceived level of effectiveness of PPE against the COVID-19 virus as moderate (39%) to very protective (54%) (186 respondents). The types of PPE that lymphoma and CLL patients have found to be effective and have used on a regular basis throughout the pandemic include masks and hand sanitizer (Figure 5).

Figure 5. Types of PPE used by lymphoma and CLL patients (186 respondents)



MENTAL HEALTH IMPACTS

The COVID-19 pandemic has not only greatly impacted the physical health of people around the world, but has also affected their psychological health, with cancer patients in particular experiencing extensive psychological distress compared to the general population. There are a number of stressors that cancer patients have had to face and manage related to their cancer care and health, in addition to the same fears and challenges the general population is experiencing related to the pandemic. Disruption of oncology services associated with the pandemic has led to higher rates of anxiety and depression²²; having less contact with physicians has been correlated with a decline in psychological wellbeing²³; and threats against job security were associated with increased depression²⁴. Further, patients with advanced refractory or relapsed disease and late-stage cancer have experienced higher levels of distress and anxiety²⁵⁻²⁶. Therefore, with the many stressors lymphoma and CLL patients are facing both in managing their cancer and the COVID-19 pandemic, there are new psychological impacts affecting patients' health that must be taken into consideration. Patients require now more than ever, resources and support to help them cope and manage their mental health to reduce the burden of impact.

"The fear in non covid times is bad enough, but the pandemic increases the strain 100-fold."

- Anonymous Patient

Here, we show a comparison of significant negative psychosocial impacts caused by the COVID-19 pandemic to lymphoma and CLL patients both at the beginning of the pandemic and over one year from the start of the pandemic. Patients rated the severity of these psychosocial impacts on a scale from 1 (no impact) to 10 (severe negative impact), with the results here showing the top three emotional challenges that have caused the greatest negative impact on the well-being of lymphoma and CLL patients (rated 7-10) (Table 1). **Of significance, vulnerability and isolation negatively impacted patients the most at the beginning of the pandemic, while worry and anxiety most negatively impact patients currently.**

Table 1. Negative psychosocial impacts to lymphoma and CLL patients caused by the COVID-19 pandemic (148-178 respondents)

Timeline	Top significant negative psychosocial impacts (percentage of patients that rated between 7-10 on the negative impact scale)		
At the beginning of the pandemic	Vulnerability (64%)	Isolation (56%)	Anxiety (55%)
Currently (more than 1 year from the start of the pandemic)	Worry (54%)	Anxiety (47%)	Stress (46%) Frustration (46%)

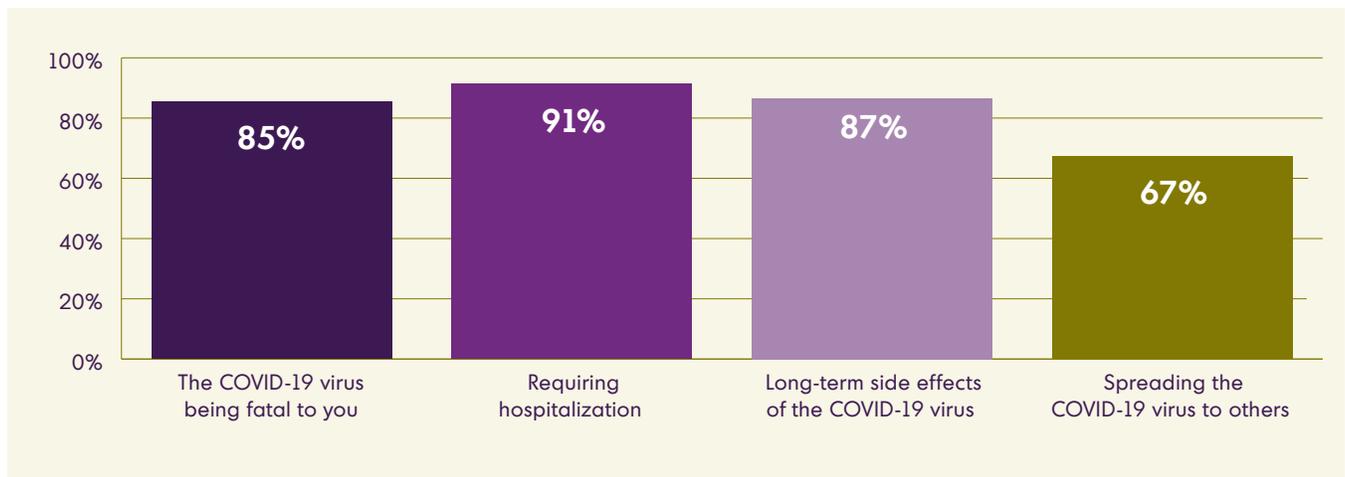
Concerns Related to the COVID-19 Virus and Health Impacts

Not only are lymphoma and CLL patients managing their physical and mental health concerns related to their cancer treatment, but they are now facing and having to manage additional physical and mental concerns related to contracting the COVID-19 virus. At the beginning of the pandemic, patients were moderately to significantly anxious around the following aspects of their lymphoma or CLL treatment:

- Fear of delays in their treatment or appointments
- Fear of disease progression and the need for continued treatment
- Fear of the inability to differentiate between the symptoms of lymphoma/CLL versus COVID-19
- Fear of not receiving treatment/hospital services for COVID-19 due to their lymphoma or CLL (i.e. lower priority or bypass for treatment compared to a patient without cancer)

Related to the COVID-19 virus and psychosocial impacts to patients even a year after the onset of the pandemic, patients are still experiencing significant fear, worry, and concern related to what would happen to their health and access to care if they contracted the COVID-19 virus (Figure 6). **Requiring hospitalization and the long-term side effects of the COVID-19 virus are of greatest concern to the lymphoma and CLL patient population.**

Figure 6. Worries and fears of contracting the COVID-19 virus (178 respondents)



There are additional concerns related to the persistence of the COVID-19 virus within the patient's community. Between 40-55% of lymphoma patients are afraid of mass community spreading and containment, worried about being in public environments (i.e. grocery store, work), and are afraid that with new strains of the virus the pandemic will never end (178 respondents).

GENERAL IMPACTS OF THE PANDEMIC ON QUALITY OF LIFE

At the beginning of the pandemic and since the nearly two years it has been ongoing, there have been numerous impacts on quality of life (QoL) caused by high viral transmission rates (i.e. self-isolation), societal closures and economic crisis. The impacts to QoL are of important consideration not only for the patient but even for a patient’s healthcare team, as a negative QoL can lead to detrimental effects both related to mental health and physical wellbeing²⁷.

At the beginning of the pandemic, patients were already experiencing significant anxiety and worry related to their ability to complete personal life goals (45%), spend quality time with their family (62%), and participate in important life moments with those they care about (70%). As time has passed, 49% of patients are still extremely worried and fearful about missing out on important life moments and goals because of the pandemic.

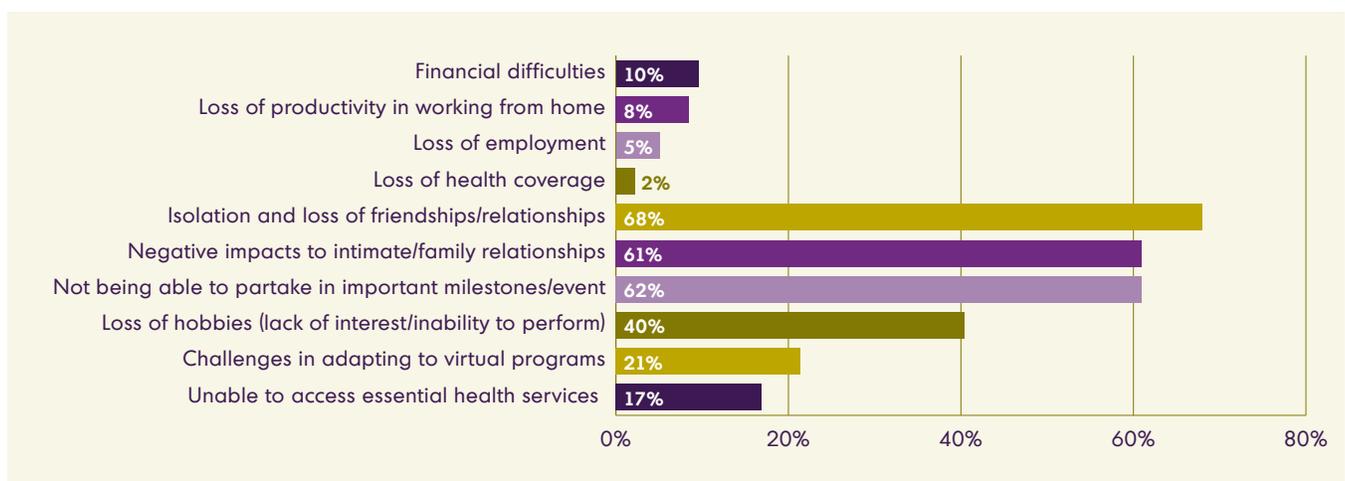
“I miss spending time with my young grandchildren and watching them grow up.”
– Anonymous Patient

“Since my treatment, spending time with my family and friends is what makes me content with life. Not being able to hug and spend time with them increases my stress.”
– Anonymous Patient

“We are a very close family and I worry that it will be a very long time before I can spend much time in the same place with my family.”
– Anonymous Patient

There are a number of general negative impacts caused by the pandemic that continue to affect patients currently (Figure 7). **The most significant and widespread negative impacts are those related to family and friendships and not being able to partake in important milestones.**

Figure 7. Negative impacts to lymphoma and CLL patients’, QoL caused by the COVID-19 pandemic (178 respondents)



Though financial difficulties have impacted a small portion of individuals, about 27% of lymphoma and CLL patients did not experience any financial difficulties, stating that they were either retired or that the pandemic instead had a positive impact on their spending patterns due to the forced closures. On the other hand, the remaining **73% of patients did experience financial impacts** as a result of the pandemic including loss of job or business (4%), reduced salary/work hours (6%), and increased financial impact related to purchasing PPE (30%) or ordering food/clothes online for safety purposes (47%) (178 respondents).

"I am not able to shop in person for food which has reduced the ability to access fresh produce etc. There is no government/provincial help to deliver food requiring additional cost of food delivery." – Anonymous Patient

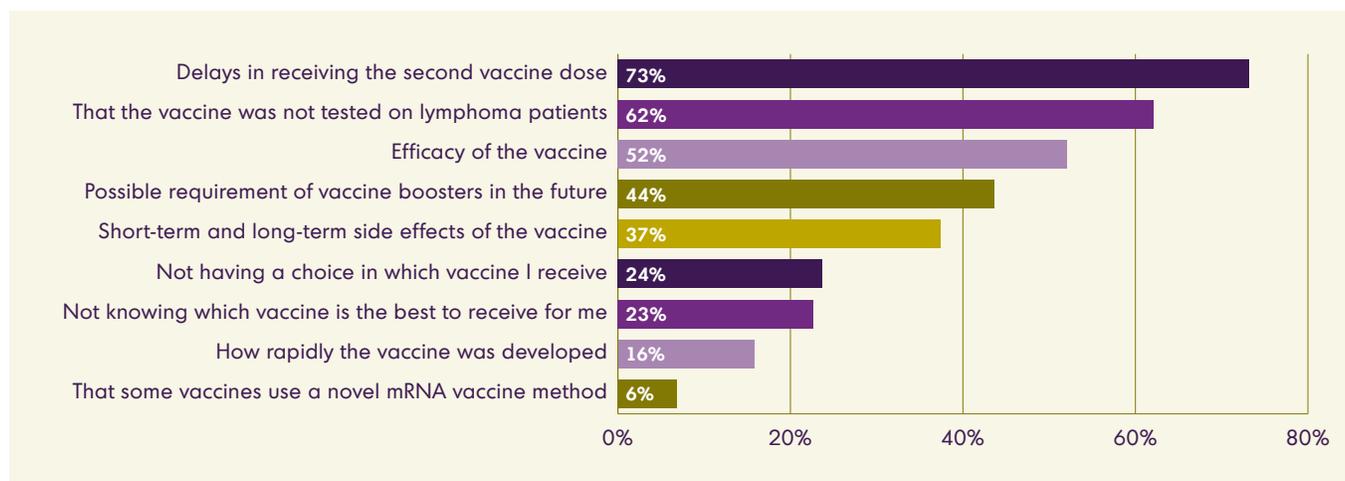
COVID-19 VACCINE EXPERIENCE FOR LYMPHOMA PATIENTS

Concerns about the Vaccine

The Canadian lymphoma and CLL community have expressed a number of concerns related to the COVID-19 vaccine. With the rapid research and manufacturing of the COVID-19 vaccines, there was a lack of available information on vaccine effectiveness and safety specific to the lymphoma and CLL population, especially as lymphoma and CLL patients and even cancer patients in general were not included in the initial clinical trials. Most information we now know about vaccine safety and effectiveness comes from real-world studies. Therefore, the lymphoma community has expressed major concerns related to the vaccine (Figure 8). **The largest concerns of lymphoma and CLL patients related to the COVID-19 vaccines are the delays in accessing the vaccines and the lack of research available on the immune response rates in lymphoma and CLL patients.**

"There should have been more testing of the vaccines on lymphoma patients. Not enough was recognised about how those with the lowered immune system can respond to the vaccine." – Anonymous Patient

Figure 8. Lymphoma and CLL patient concerns related to the COVID-19 vaccines (190 respondents)



Lymphoma Patient Experience Receiving the Vaccine

Important information on the lymphoma and CLL patient experience when receiving the vaccine(s) was collected through the most recent one-year follow-up Lymphoma Canada experience survey. There were 89% of 178 respondents that had received their first vaccine, while only 23% of 159 respondents that had received their second vaccine at the time. Patients had received the Pfizer-BioNTech (81%), Moderna (11%) and AstraZeneca (8%) vaccines in Canada (159 respondents). Patients did not experience a significant delay in obtaining their first COVID-19 vaccine and were able to receive it as soon as it became available to them (85%; 159 respondents). The majority of patients booked their vaccine online (59%) or called their provincial immunization hotline to book their appointment (14%). In a small portion of individuals, there were delays in receiving this first dose as a result of local availability (12%), their lymphoma treatment (2%) and/or health concerns (1%).

Though the majority of lymphoma and CLL patients did not experience challenges in accessing the first vaccine, the same could not be said for the second vaccine. Lymphoma and CLL patients were not initially prioritized upon the release of provincial immunization plans for the second vaccine, and patient advocacy groups, and even patients themselves, were advocating for urgent access to the second vaccine. Access has been a priority for patients as clinical trials published on the mRNA vaccines involved second vaccine dose administration between 21 or 28 days following the first vaccine for best and tested clinical effectiveness and safety. Unfortunately, with vaccine shipment and distribution challenges across Canada, the National Advisory Council on Immunization (NACI) had declared that the second vaccine could be administered within four months of the first vaccine dose without support at the time of published research on COVID-19 vaccine effectiveness with delayed dosing in cancer patients. With immunocompromised patients already having a reduced immune response following the initial vaccine compared to the general population^{17-19, 28-31}, accessing the second vaccine dose has never been more important. The majority of patients (74% of 159 respondents) did indicate they experienced a delay in accessing the second vaccine for reasons which included government policies preventing access (52%), difficulties with local and institutional access (25%), and their lymphoma treatments and health (9%). **It must therefore be recognized that lymphoma and CLL patients may continue to experience challenges and delays in accessing future doses of the COVID-19 vaccines if required and recommended by their clinician based on the way that provincial policies and immunization plans have rolled out vaccine administration in the past.**

"Delays in receiving the second vaccine dose" is a huge problem for cancer patients. We realize this has been raised by Lymphoma Canada but must be prioritized by everyone."

- Anonymous Patient

Patients provided additional information related to their experience receiving the vaccines. After receiving either the first or second dose of the vaccine, **the most common side effects experienced by lymphoma and CLL patients included pain at the site of injection, tiredness/fatigue and headaches.**

Access to Appropriate Vaccine Information

A large contributor to the fear and concern patients experience related to the COVID-19 vaccines has been due to the lack of lymphoma- and CLL-specific research and access to this information, as well as variable implementation and access strategies across the country. Clinical research is often complex, and it may be difficult for lymphoma and CLL patients to understand and interpret information presented in a scientific research paper. Further, many patients have reported challenges in having thorough conversations with their healthcare team due to time constraints, and many individuals are instead receiving their information about the pandemic and vaccines from more public sources which may not always be reputable or credible. Lymphoma and CLL patients shared how they currently receive information about the COVID-19 virus and vaccines. **The majority of patients (84%) receive their information about the pandemic and vaccines from news reports and press releases.** This shows that patients are not necessarily receiving important and patient-specific information about the pandemic and vaccine from their healthcare team. The remaining sources of information that patients utilize include government guidelines (62%) and online searches through Google (53%), followed by more reputable sources such as research articles (46%), patient organizations (41%), and their doctor and healthcare team (37%) (190 respondents).

"I feel it has been totally up to me to research about Covid and it's effects on immune compromised patients... neither my government or health team offered me any advice beyond get whatever vaccine is offered. I feel very let down how little information or direction I was given." – Anonymous Patient

It is also important to understand the type of information that patients find valuable and how to get this information to patients. **The lymphoma and CLL community have indicated that they would like to receive information on the following COVID-19 and vaccine topics in order of importance:**

1. Long-term immune response and boosters for the COVID-19 vaccine
2. Efficacy of the COVID-19 vaccine (i.e. immune response)
3. Risk of contracting the virus for patients with lymphoma or CLL
4. Severity of COVID-19 symptoms in patients with lymphoma or CLL that have contracted the virus
5. Side effects of the COVID-19 vaccines

Further, patients would like to receive this information from more reputable sources such as their healthcare team and patient organizations (Table 3).

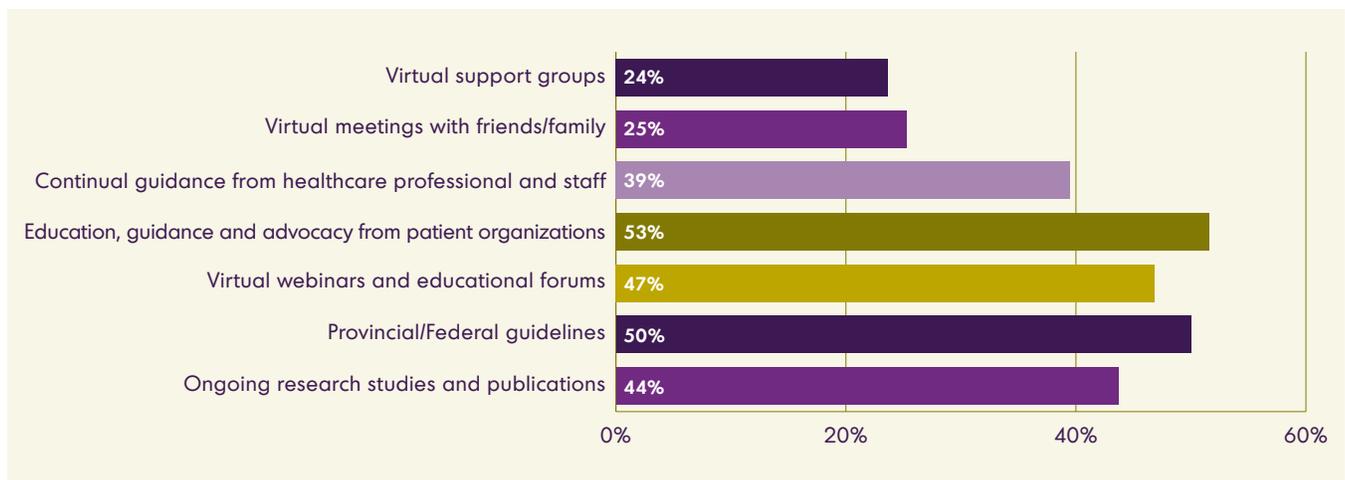
Table 3. Sources that lymphoma and CLL patients would like to receive information from about COVID-19 (190 respondents)

65%	From my doctor and healthcare team/hospital
55%	From patient organizations
32%	News reports and releases
31%	From published research articles
17%	In a letter sent to me by the government

SUPPORT AND INFORMATION FOR LYMPHOMA AND CLL PATIENTS THROUGHOUT THE COVID-19 PANDEMIC

Many cancer patients feel the added stress of the pandemic and its impact on their wellbeing. There are certain populations of cancer patients that are more worried about contracting COVID-19 and its impacts on their health rather than the impacts of their cancer, especially those with long-term disease³²⁻³³. Because of the many psychosocial impacts that cancer patients have had to face during the pandemic, this has resulted in significantly lower self-reported quality of life compared to the general population³⁴. As such, resources and support systems are required now more than ever for Canadian cancer patients. Lymphoma and CLL patients have shared the different resources and information sources that have helped them in managing both their physical and mental health throughout the pandemic (Figure 9). **Patients have noted that education, guidance and advocacy efforts from patient organizations, such as Lymphoma Canada, have provided the greatest support to them throughout the pandemic.** Other important educational resources that have helped the lymphoma and CLL community include the release of provincial/federal guidelines (50%), virtual webinars and educational forums (47%), and guidance from healthcare professionals (39%).

Figure 9. Helpful education and support that lymphoma and CLL patients received during the pandemic (190 respondents)

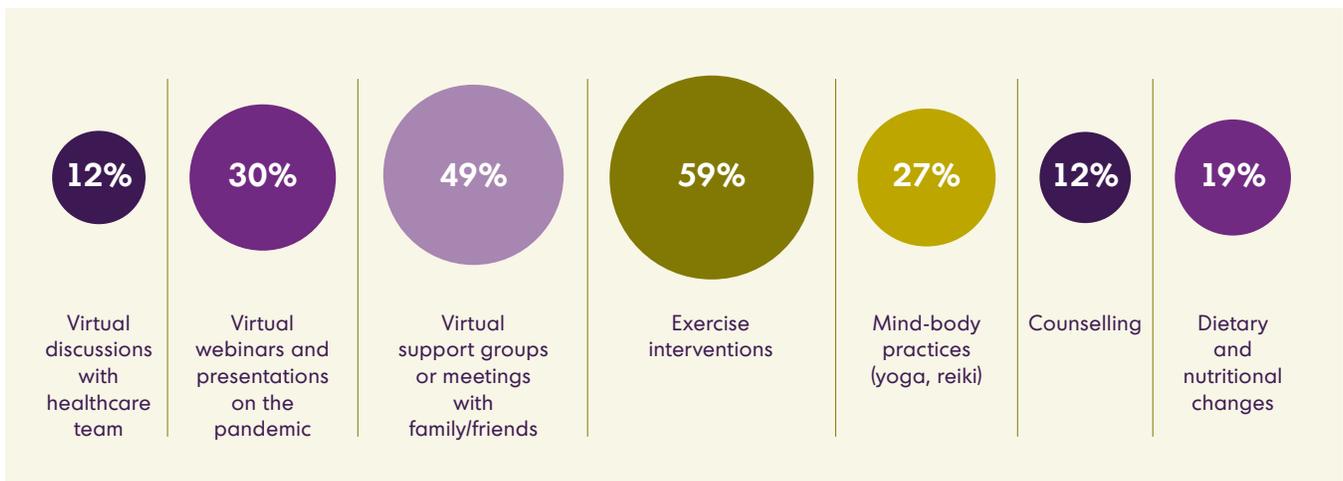


With the number of mental health impacts that lymphoma and CLL patients experience (listed in the section on *Mental Health Impacts*), there are a number of coping mechanisms that patients have employed to reduce the burden of impact (Figure 10). **Exercise interventions and virtual educational opportunities (i.e. support groups, meeting with family/friends, webinars) have been the most useful in helping patients to manage the detrimental and difficult psychosocial impacts of the pandemic.**

"I have decided things I can't control are not worth worrying about. If it happens, I will worry then."

- Anonymous Patient

Figure 10. Coping mechanisms to help with mental health (178 respondents)



PATIENT GUIDANCE FOR IMPROVING EXPERIENCE

Patients provided valuable information on what they feel needs to be done to improve their experience in managing their physical and mental health throughout the COVID-19 pandemic (Table 4) (155-186 respondents).

Table 4. Lymphoma and CLL patients provide guidance on how to help improve their experience throughout the COVID-19 pandemic.

Action Item	Specific Topics for Action Item to Address
Increased research efforts specifically for cancer patients (90%)	<ol style="list-style-type: none"> 1. Long-term immunity following the COVID-19 vaccines in lymphoma and CLL patients (specific to subtype, treatments, etc.) 2. Vaccine effectiveness with different time delays between 1st, 2nd, 3rd, etc. vaccine doses 3. Comparatives studies on the effectiveness and safety of the different vaccines in lymphoma and CLL patients 4. Long-term effects of contracting the COVID-19 virus in lymphoma and CLL patients 5. Tests to determine vaccine effectiveness and how to interpret the results
Improved translation of educational information from preferred sources (72%)	<ol style="list-style-type: none"> 1. Letter or email from healthcare team (promptly) 2. Government or provincial health ministry or cancer agency guidelines distributed directly to patients 3. Patient organizations (e-mail, webinars, etc.)
Increased educational resources on important information topics (69%)	<ol style="list-style-type: none"> 1. Effectiveness of the vaccine depending on lymphoma subtype and treatments, or for those in remission (i.e. best timing to receive the vaccine) 2. Side effects from the vaccine (short and long-term) and management techniques 3. Requirement for additional vaccines and consistency in booking procedures 4. COVID-19 virus variants and risks and impacts to lymphoma patients 5. Information directed to Canadian patients in particular
Increased advocacy efforts by patient groups and healthcare teams across all provinces (62%)	<ol style="list-style-type: none"> 1. Lack of vaccine effectiveness compared to the general population and the requirement for continued protection and social distancing measures to protect the cancer population 2. Access to clinical trials for blood cancer patients in Canada and new treatments 3. Higher priority in getting access to the vaccine without delay for all lymphoma and CLL patients 4. Higher priority access to the vaccines for household family members of those with lymphoma and CLL 5. More local support groups and resources for lymphoma and CLL patients
Increased support systems (47%)	<ol style="list-style-type: none"> 1. Educational support through healthcare team, patient groups, government, etc. 2. Access to mental health support groups that provide coping and management techniques 3. Virtual support systems such as chat rooms or local support groups that should exist in hybrid models even following the pandemic for those without local access. 4. Access to individual counsellor support

“Simply not enough is being done in the field of cancer patients/survivors and the impact of the pandemic.”
 – Anonymous Patient

“I feel that advocacy groups need to talk about how their members are vulnerable... People need to know that for us this is not going away and that the vaccine does not work in the same way – some of us will have to get used to a new normal – again.”
 – Anonymous Patient

With the number of excellent suggestions provided by lymphoma and CLL patients on their needs related to education, support, research and advocacy, collaborative efforts are underway to develop targeted programs and services that address the highlighted issues experienced by the Canadian patient community.

Lymphoma and CLL patients have provided action items on the programs and services that would support them through the pandemic. **This includes increased research efforts specifically targeted towards lymphoma and CLL patients, improved translation and access to relevant education information from preferred reputable sources, increased number of educational resources on important information topics, increased advocacy efforts by patient groups and healthcare teams across all provinces, and increased number and access to local support systems.**

Summary of Key Findings for the Patient Experience

<p>Healthcare Impacts</p>	<ul style="list-style-type: none"> Approximately 22% of patients found their follow-up care, including monitoring tests and procedures, to be negatively impacted by the pandemic through either cancellation, decreased frequency, or lack of communication on the results. Approximately 16% of patients indicated access challenges with treatment options or even challenges in continuing on their current treatment plan. Nearly all patients had non-treatment related appointments changed to virtual appointments. However, patients reported that they prefer to have in-person follow-up appointments to ensure physical examinations are performed to monitor lymph nodes and overall health.
<p>Personal Care</p>	<ul style="list-style-type: none"> The majority of lymphoma and CLL patients (62%) feel at risk going to the hospital or doctor's office during the pandemic; of greatest concern was the risk from exposure to asymptomatic healthcare workers. Patients perceived the effectiveness of PPE against the COVID-19 virus as moderately (39%) to very protective (54%), with masks and sanitizers as the most used and effective.
<p>Mental Health</p>	<ul style="list-style-type: none"> Vulnerability and isolation negatively impacted lymphoma and CLL patients the most at the beginning of the pandemic, while worry and anxiety most negatively impact patients currently. The majority of patients are worried/concerned that their cancer treatments would increase their risk of contracting the virus as they will be further immunocompromised. Requiring hospitalization and the long-term effects of the COVID-19 virus are of greatest concern to the lymphoma and CLL patient population.
<p>Quality of Life</p>	<ul style="list-style-type: none"> At the beginning of the pandemic, patients were already experiencing significant anxiety and worry related to their ability to complete personal life goals (45%), spend quality time with their family (62%), and participate in important life moments with those they care about (70%). 49% of patients are still worried and fearful about missing out on important life moments and goals.
<p>Support</p>	<ul style="list-style-type: none"> Patients have noted that education, guidance and advocacy efforts from patient organizations, such as Lymphoma Canada, have provided the greatest support to them during the pandemic. Exercise interventions and virtual educational opportunities (i.e. support groups, meeting with family/friends, webinars) have been the most useful in helping patients to manage the psychosocial impacts of the pandemic.
<p>COVID-19 Vaccine</p>	<ul style="list-style-type: none"> The largest concerns of lymphoma and CLL patients related to the COVID-19 vaccines are the delays in accessing the vaccines and the lack of research available on the immune response rates in lymphoma and CLL patients. The majority of patients (74%) did indicate they experienced a delay in accessing the second vaccine for reasons which included government policies preventing access (52%), difficulties with local and institutional access (25%), and their lymphoma treatments and schedule (9%). The majority of patients (84%) receive their information about the pandemic and vaccines from news reports and press releases, however patients would like to receive this information (i.e. long-term immune response, risks for contracting COVID-19, etc.) from more reputable sources such as their healthcare team and patient organizations.

Caregiver Experience

Lymphoma and CLL Canadian Caregiver
Experience during the COVID-19 pandemic



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Caregivers provide a valuable source of support to lymphoma and CLL patients. According to the **Lymphoma Canada Caregiver Report**, caregivers help the patient they are caring for in many different ways: providing emotional support, researching information about lymphoma or CLL, accompanying the patient and providing transport to and from appointments, running errands for the patient, and helping with daily tasks. Pre-COVID-19 data has shown that caregivers help with 70-89% of care needed by cancer patients³⁶.

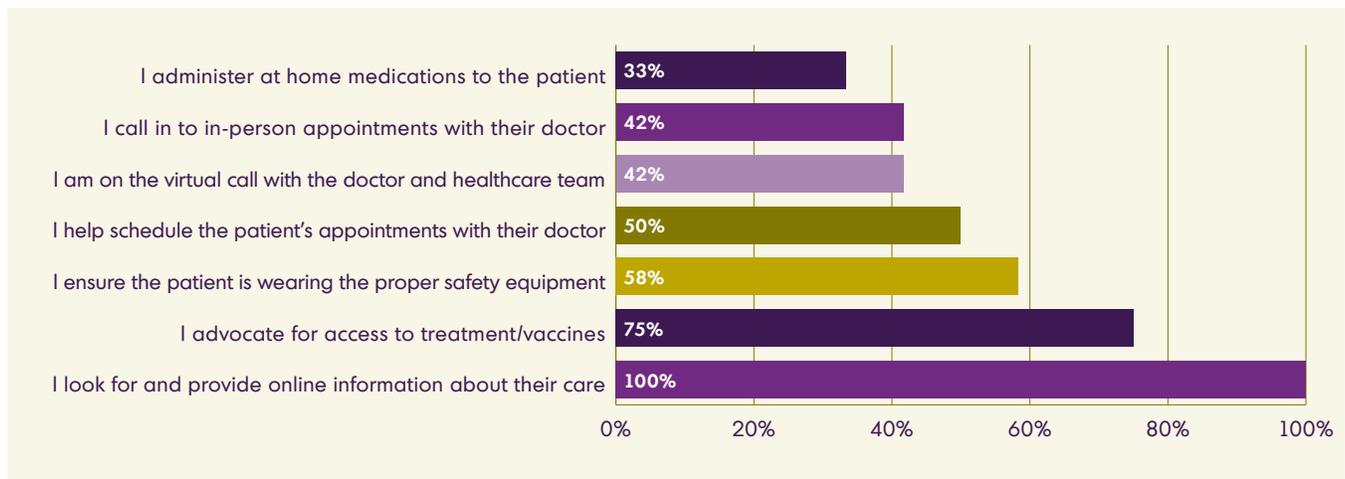
With lymphoma and CLL patients being particularly vulnerable to the COVID-19 virus, owing to the nature of their disease and the impacts of certain immunosuppressive treatments, caregivers now shoulder a **triple the burden**: the COVID-19 pandemic, increased healthcare needs from the patient, and an elevated need for physical and psychological care themselves³⁷. It is therefore important to address the needs and challenges facing the caregiver community to provide valuable support that will help to improve their own wellbeing and their ability to provide support and care for their loved ones.

“There is not enough support - care partners are expected to know so much and also our healthcare system just expects the care partner to be there and available to support the patient and that is not ok.” – Anonymous Patient

Involvement of Caregivers in the Health and Wellbeing of Lymphoma and CLL Patients

Caregivers are involved in helping their loved ones access care and manage their health, and have been doing so throughout the COVID-19 pandemic by providing educational and advocacy-related support for their loved ones (Figure 11). **All caregivers (100%) helped the patient by researching important information about their care.**

Figure 11. How caregivers help lymphoma and CLL patients (12 respondents)

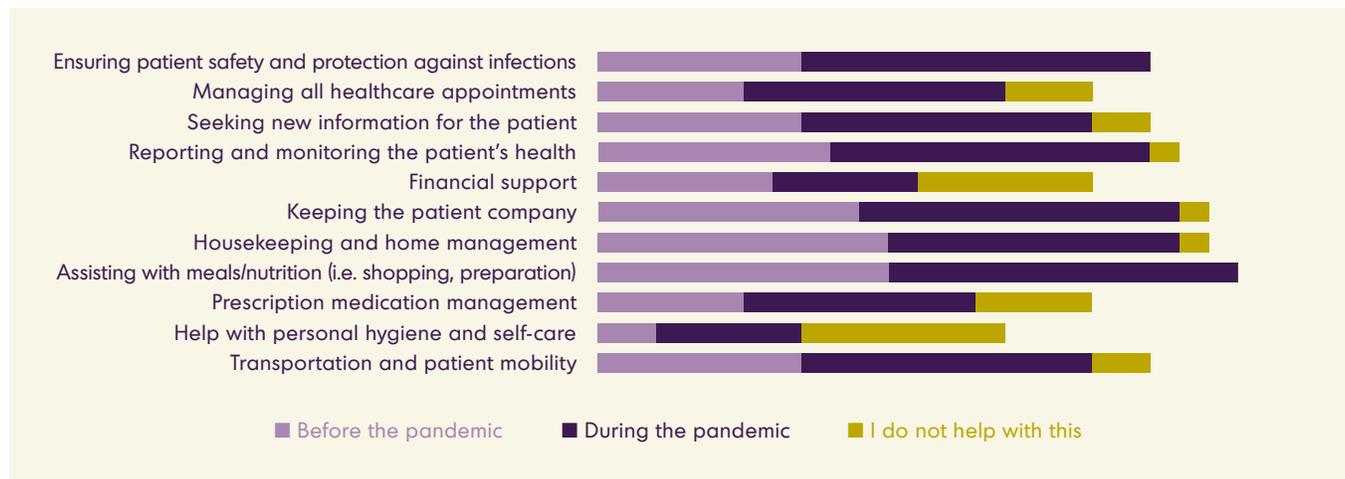


An unfortunate consequence of the pandemic for the patients attending in-person healthcare appointments is that they must now do so alone. Visitors have been limited or completely excluded from attending appointments with the patient, and are therefore unable to provide valuable support and assistance. This has impacted not only the patient but the caregiver as well. Different techniques have been used to try and provide some type of supportive role in this scenario: having the patient call the caregiver while in the appointment, using virtual video technology programs (facetime, zoom, etc.) to call the caregiver during the appointment, bringing a list of questions from the caregiver to the doctor for an answer, recording the conversation with the doctor to share with the caregiver later (with the doctor’s approval), etc. Though these methods are not the same as in-person support, they may help the caregiver be involved throughout the patient’s healthcare appointments.

“Being unable to attend appointments with the patient was **EXTREMELY** challenging and upsetting. My loved one would be overwhelmed with the medical terminology and listening in did not allow me to be as involved. Also being unable to provide in-person support during many rounds of chemo and a stem cell transplant was isolating for both of us.” – Anonymous Patient

There are a number of ways that caregivers have assisted patients both before and after the pandemic (Figure 12). **Notably, with nearly all of the many ways that caregivers have helped patients prior to the pandemic, these have increased anywhere from 16-42% in their frequency during the pandemic.** The greatest percent increases include ensuring patient safety and protection against infections (42% increase) and managing all healthcare appointments (33% increase). Caregivers provide a wealth of support, education and advocacy for lymphoma and CLL patients to help them cope with and manage their cancer.

Figure 12. Caregiver assistance provided before and during the pandemic (12 respondents)



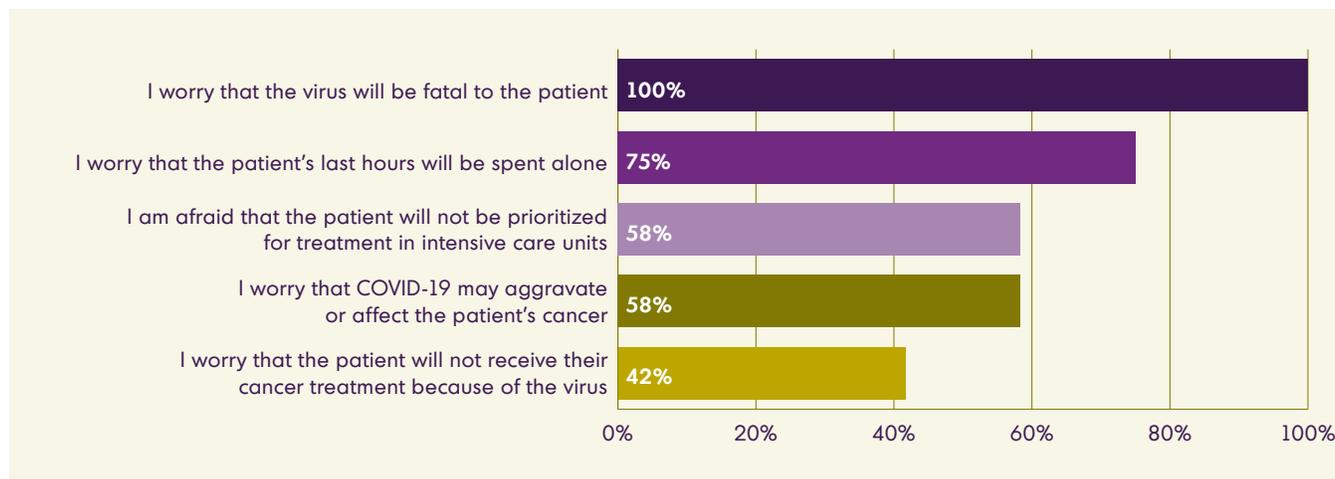
Psychosocial Impacts of the COVID-19 Pandemic to Caregivers

Though caregivers provide valuable support for lymphoma and CLL patients, caregivers can be equally affected by the role of caregiving. It is important that caregivers look after themselves in order to be able to best look after the patient they are caring for.

The Lymphoma Canada survey revealed that 50% of caregivers were significantly concerned about passing along the COVID-19 virus if they contract it to the lymphoma or CLL patient they care for. There are a number of additional concerns expressed by caregivers related to the COVID-19 virus and its impacts (Figure 13). All caregivers were worried that the COVID-19 virus would be fatal to the patient if they contract it.

“Although I have been following the provincial guidelines and trying to isolate as best I can prior to my dad’s diagnosis & treatment, I still have to go to the grocery store and take him to all his HCP appointments where sometimes social distancing can be a challenge. I worry that I may inadvertently be exposed and transfer it to my dad.” – Anonymous Patient

Figure 13. Concerns of caregivers if they or the patient contract the COVID-19 virus (12 respondents)



Though there are many negative impacts associated with the COVID-19 pandemic, it is important to note that caregivers expressed certain “silver linings” of the pandemic. This included the ability to spend more time together, trying new things, and feeling that the patient is safer because of the community precautions that have been implemented (i.e. social distancing, masks, etc.)

“COVID forces people to be masked therefore there is a lower chance of contracting the virus for someone whose immunity is compromised.”

– Anonymous Patient

Summary of Key Findings for the Caregiver Experience

How Caregivers Supported Patients	<ul style="list-style-type: none">• All caregivers helped the lymphoma or CLL patient they care for by researching important information about their health and care.• With all of the many ways caregivers have helped patients prior to the pandemic, these have increased anywhere from 16-42% in their frequency during the pandemic, with the greatest increases being ensuring patient safety and protection against infections (42%) and managing all healthcare appointments (33%).
Psychosocial Impacts to Caregivers	<ul style="list-style-type: none">• Many of the psychosocial impacts reported by caregivers were related to the lymphoma or CLL patient they care for:<ul style="list-style-type: none">• 50% of caregivers were significantly concerned about passing along the COVID-19 virus to the lymphoma or CLL patient if they contract it.• All caregivers were worried that the COVID-19 virus would be fatal to the patient if they contract it.

Conclusion

The COVID-19 pandemic has upended cancer care and the overall cancer experience, and without the end of the pandemic in sight, it is important to continually analyze the impacts of the pandemic and identify improvements to address the needs of patients and caregivers, as well as the healthcare system as a whole.

Every stage of the cancer journey has been impacted by the COVID-19 pandemic, from diagnosis to treatment and follow-up care into survivorship. The many key findings of this report highlight the needs and challenges facing the Canadian lymphoma and CLL patient and caregiver community. A collaborative and active approach to address these challenges will bring forth vital improvements for this community and will further help put in place important resources and supports for patients and caregivers that are much needed within cancer care in general.

WAYS TO SUPPORT PATIENTS AND CAREGIVERS

Patient organizations have remained a stable and important source of valuable information and support for patients and their families throughout the COVID-19 pandemic. Not only have patient organizations helped patients to navigate through virtual care, but they have provided a number of educational opportunities that address current questions related to the pandemic and other important lymphoma or CLL-specific topics of interest. With the reduced amount of time that patients have with their healthcare team and the lack of access to in-person resources that they would have normally received through in-hospital visits, patient organizations are there to provide lymphoma- and CLL-specific information from reputable resources. Patient organizations strive to continue to support patients through numerous education, support, advocacy and research opportunities. Though there are specific lymphoma and CLL-related concerns and impacts due to the pandemic, many of these affect the cancer community as a whole, and collaborative approaches to providing support can enact change on a national scale.

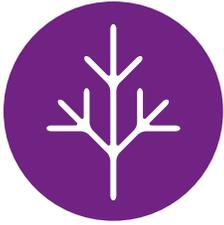
There are a number of different approaches that can be implemented to provide support that will address the negative impacts of the COVID-19 pandemic. There are numerous healthcare needs, including how to provide patients with safe opportunities for thorough conversations and fulsome physical assessments with their healthcare team. Frequent and timely testing for a diagnosis, during treatment and follow-up assessments during remission, needs to be a priority to ensure best standard of care practices. Further, treatment approaches should be tailored to meet the individual needs of each patient, ensuring that they are receiving the best treatment available that aligns with their needs while staying safe and protected against the COVID-19 virus; systems must be put in place to prevent the pandemic from impacting healthcare. There are a number of methods that must be employed to continue to provide patients and caregivers with psychosocial support, ensuring that no matter where these individuals are located across Canada, they will have the opportunity for local access without financial implications. As patients have requested, research must continue to understand the COVID-19 health impacts and vaccine safety and effectiveness specific to the lymphoma and CLL patient population.

Lymphoma does not stop during the pandemic, but with collaborative efforts, we can work together to improve the overall patient and caregiver experience by developing valuable programs and services that will address the needs and challenges of the lymphoma and CLL community to even surpass the care and support that existed prior to the pandemic. Lymphoma Canada will strive to address the patient and caregiver needs expressed in this report to provide appropriate and relevant programs and services to reduce the impacts of the COVID-19 pandemic on the health and wellbeing of the Canadian lymphoma and CLL community.

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