

Long COVID: Literature Scan to Inform Policy Response in the GTA

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INTRODUCTION

Two and a half years into the pandemic we are learning more about a portion of the population that continues to suffer from ongoing symptoms following acute illness with COVID-19.¹ The long COVID condition impacts multiple organ systems, and results in a wide range of symptoms (e.g., extreme fatigue, cognitive difficulties, shortness of breath, heart palpitations), which in some cases can be severely debilitating.²

Regardless of the predominant attitude that the pandemic has "ended," long COVID represents the evolving impact of the virus on society as we continue to navigate its inherent uncertainty. Gaps in understanding of long COVID should not be used as a rationale for a delayed response to meet the health and social needs of those suffering from the condition. This is especially the case because inaction is likely to further contribute to inequities that have become starkly evident during the pandemic.

Considering the evidence that long COVID symptoms negatively impact the functioning of a substantial portion of the population in Canada and internationally, attention to the following four broad areas is needed to provide supports to people with disability caused by the coronavirus:

1. Access to healthcare services
2. Workplace accommodations and conditions
3. Income supports
4. Community-based care and supports

This paper draws from a scan of research and literature on long COVID to outline these key areas for health and social policy decision-making. For each area, a brief summary of the research and corresponding pathways forward is discussed. The analysis then highlights the importance of prioritizing equity and considers how inequities may be exacerbated or remediated by policy responses. Some examples of responses from other jurisdictions are also provided.*

The evidence base about long COVID is fast evolving, with findings from new studies being published regularly. The purpose of this scan is to bring together existing knowledge to consider in the development of policy that facilitates health and social equity, with the idea that this is a jumping off point for developing deliberation.

* A scan of international and Canadian policy from early 2022 revealed a substantial gap in programs specific to long COVID that addressed the broad support needs outlined in this paper. For this reason, the paper includes relevant policy responses from other jurisdictions that may benefit people living with long COVID-19. These responses are not systematically evaluated or intended to represent 'best practices,' but instead are meant to act as a starting point for thinking more specifically about policy responses to long COVID.

BACKGROUND

Considerable gaps in knowledge about long COVID continue to exist, including the underlying biological mechanisms and causes, physiological risk factors, and the progression and outcomes of the condition. Despite this uncertainty, the following definition of “post-COVID-19 condition” from the World Health Organization is widely used and draws from international consensus on clinical definitions: the *persistent* or *new* onset of symptoms after 3 months following SARS-CoV-2 infection.³

Conservative estimates from 2021 suggest that between 57,000 and 78,000⁴ individuals in Ontario and around 150,000⁵ Canadians had had or were currently experiencing the condition. There is a wide range in prevalence estimates internationally.⁶ Population data from Britain suggests that 22 per cent to 38 per cent of people with the COVID-19 infection will have at least one ongoing symptom 12 weeks after initial symptom onset, and 12 per cent to 17 per cent will have three or more symptoms.⁷ With these estimates and ongoing infection rates, it is likely that the long COVID numbers in Canada and Ontario have increased over the past year.

Long COVID is associated with increased use of health care resources, and adverse impact on work and activities of daily living. An international survey of people with long COVID symptoms lasting more than 28 days, found that 91 per cent of respondents had ongoing symptoms that exceeded seven months in duration.⁸ The prolonged health impacts have the potential to require diverse resources for recovery, including clinical health services such as rehabilitation, mental health services, in addition to social supports and other resources to help with maintaining roles and social participation.⁹

Although studies recognize that people experience diverse symptoms, in-depth analyses of long COVID inequities remain few. Despite this, some research does acknowledge that ongoing effects linked to COVID-19, including persistent symptoms, are strongly influenced by social determinants such as poverty, social disadvantage and structural inequality.^{10,11}

The effects of the pandemic have been highly inequitable in Ontario, as COVID-19 infections have disproportionately impacted members of racialized communities, those with low incomes and essential workers, and have resulted in inequitable health outcomes for these groups.^{12,13} For example, rates of hospitalizations have been disproportionately higher for some racialized populations in Toronto compared to their white counterparts.¹⁴ Although people with mild symptoms can develop long COVID, there is an observed positive relationship between the severity of acute symptoms and greater risk of long COVID.¹⁵

There are also certain factors that have been associated with poorer outcomes from COVID-19 in which the burden may be borne more by some social groups, such as higher rates of comorbidities (e.g., asthma, diabetes).^{16,17,18} Many of the inequities we have seen unfold since early 2020 will no doubt continue to manifest in long COVID experiences and outcomes, and marginalized groups are likely to experience a more intense manifestation of illness due to the lack of access to supportive social and economic conditions.

Underlying social and economic factors shape inequities in experiences, rates and outcomes of long COVID. These factors influence the risk of getting COVID-19, access to health and social care and supports to treat COVID and long COVID, and the effectiveness of treatments and supports. With this in mind, it is likely that exposure to poorer material conditions will result in a higher risk of long COVID and poorer outcomes from long COVID.¹⁹

Acknowledging these stages serves as an important reminder that long COVID inequities are not just the result of something that happens in the post-acute phase. This paper focuses primarily on research that looks at long COVID as opposed to the acute phase but also recognizes that interventions to address inequities more broadly (e.g., in risk and outcomes linked to acute COVID) will be important for addressing long COVID inequities in their entirety.

ACCESS TO HEALTHCARE SERVICES

What we know and directions forward

The literature recognizes a broad range of symptoms experienced by people with long COVID. There is also variation in severity of symptoms and their impact on overall health and functioning.²⁰ Some researchers also draw attention to the fact that long COVID can be understood as an “episodic disability” for some, where people have fluctuations in symptoms and health (e.g., symptoms can improve and then worsen at a later time).²¹

Primary care is often the first point of entry into the healthcare system for patients suffering from long COVID.^{22,23} Primary care is crucial to addressing long COVID, from initial assessment and diagnostics, to providing medical management and support in self-management, and specialist referral, in addition to help with navigating the healthcare and other systems (e.g., social and income programs), including public long COVID clinics or programs.^{24,25,26} Access to appropriate healthcare for people suffering from long COVID should be available to both those who have been hospitalized and non-hospitalized patients with long COVID.²⁷

Care models for people with long COVID have been implemented across various national contexts since early in the pandemic. One rapid review of international care models for people living with long COVID found that common components of programs included multidisciplinary teams, with integrated care pathways (e.g., between primary care, rehabilitation services and specialized clinics for medical assessment), follow up systems and virtual care approaches.²⁸ A main conclusion of the review is that centralized referral systems could enable entry into necessary care pathways. Despite this knowledge, significant barriers and access issues have been reported for programs that do exist. These include long wait times and a lack of capacity, as well as a lack of care programs in many jurisdictions.

Many people with long COVID report that the symptoms and condition have a considerable negative impact on their mental health and sense of well-being.^{29,30} With this knowledge and given what we have seen facing populations during the pandemic, mental health referral and corresponding programs with capacity should be a priority within the multidisciplinary, integrated care models mentioned above.

The few early examples of qualitative research from other jurisdictions suggest that considerable improvements are required to adequately address the health-related needs of long-COVID patients.^{31,32} Patients consistently describe the considerable work that they must undertake to manage symptoms, engage with healthcare systems, and advocate for themselves to receive the care that they need. Some of the difficulties that they encounter include uncertainty and lack of knowledge about the condition and corresponding protocols from healthcare providers.^{33,34} Another key challenge is the lack of programs available to them.³⁵

Given that primary care providers are critical points of support for patients around healthcare and other social factors (e.g., decisions about return to work),³⁶ physicians and other healthcare providers require support and information regarding their role in assessment, treatment and referral. One broad solution in this regard is centralized resources for clinicians, as well as public or community education on healthcare and social and economic programs available for those experiencing ongoing symptoms following acute COVID-19.³⁷ A stepped care approach which integrates primary care to specialist services defined by clear

treatment protocols and pathways may be a way forward to mimic a centralized system in Ontario.

Given the diversity in experiences of long COVID, the uncertainty of its prognosis, and the evolving state of knowledge about the condition, it follows that clinical and other definitions upon which access to health and other benefits are contingent, should be as inclusive and open as possible. The development and operationalization of these definitions need to involve a broad range of perspectives from different groups, including those from communities that have been hardest hit by the pandemic.

Equity considerations

Health and social equity considerations need to be prioritized in healthcare responses to long COVID. As described, the scarcity of long COVID clinics will have a greater impact on populations that already face considerable barriers accessing the healthcare system, especially those facing inequities based on intersecting factors such as racialization, income, disability, and gender.

Although consideration of inequities in long COVID in the literature remains sparse, some researchers recognize that experiences of prolonged COVID-19 symptoms may vary by social group (e.g., Black communities in Toronto).³⁸ They highlight that the management and treatment of long COVID symptoms requires special attention to cultural and contextual factors that are barriers to engaging in mainstream health and care.^{39,40} It follows that anyone facing discrimination, stigma, lack of linguistic or culturally safe options within the healthcare system would be disadvantaged in navigating access to long COVID care.

People facing economic barriers, low incomes, or those unable to afford time off work to recover could experience delays in care, which might negatively impact them if early intervention improves short and long-term outcomes. Individuals with fewer resources and competing priorities (e.g., work, caregiving, domestic duties) will be disadvantaged in a system where access to care can be onerous, even for those with considerable resources. There is a need to design health services so that social and economic conditions do not determine access.

As mentioned, access to a range of interdisciplinary health and well-being services (often within one location) has been identified as an important healthcare intervention for this multisystem illness, and in contexts where other healthcare services (e.g., rehabilitation, counselling, acupuncture) are scarce or not universally covered, those with economic capital who are able to pay-out-of-pocket or who have healthcare benefits through employment will have access to a superior level of care.⁴¹ Inequities in access to digital technologies (e.g., internet, computers) are also a potential economic barrier to care, when many self-management and other programs are offered online.⁴²

Specific populations with relative advantage have been over-represented in early research on experiences of long COVID (e.g., higher income and education levels, fewer barriers to access to digital platforms, and non-racialized individuals).^{43,44} In Canada, it has been reported that insufficient investment has caused delay in gaining access to long COVID programs.⁴⁵ Where research studies enable access to experimental and scarce health programs, there is potential for heightened inequities, where patients with greater access to resources, higher levels of education, stronger ties with primary care providers to advocate for them, will likely have an easier time accessing these studies. The eligibility requirement for a positive test for some studies may offer further barriers for some, such as groups with low income. This is especially the case in Ontario where tests have been difficult to access for free but are often available for out-of-pocket purchase.

Planning for the necessary expansion of long COVID health and social services must simultaneously address inequities by reducing barriers to care. The location and delivery of services will be important considerations. For example, “one-stop” locations where people can receive all health and social and economic supports has been identified as important for reducing barriers,⁴⁶ while some communities or groups may require more direct outreach in the identification of who needs long COVID supports and in the delivery of these supports. A potential model for an outreach approach was demonstrated through the vaccine equity outreach teams in Toronto that sought to improve access for populations that are underserved and facing barriers to vaccination.^{47,48} These kinds of approaches could also allow flexibility to integrate a range of necessary supports related to long COVID that are driven by individual circumstance and need.

Example of a policy response: National Health Service (NHS) England

As the challenges of long COVID were first becoming evident in 2020, the [National Health Service \(NHS\) England](#) responded by releasing a 5-point plan that focused on establishing and expanding access to specialized health services and supports. It included: new guidance commissioned by the National Institute for Health and Care Excellence (NICE) on the “case definition” of long COVID along with clinical guidelines to support NHS doctors and staff in providing treatment; an online referral-based rehabilitation service called “Your COVID Recovery”; the establishment of Post-COVID Assessment Clinics; funding for long COVID research; and the creation of the NHS England Long COVID taskforce to help guide the plan’s implementation.

In 2021, [NHS England and NHS Improvement](#) announced additional funding and new measures to support long COVID management. Central to this was £70 million to expand long COVID services beyond comprehensive medical assessment, to additionally provide multidisciplinary rehabilitation services. Additional new measures included funding for enhanced service for general practice to support primary care and referrals, specialized Post-COVID assessment for children and youth, and collection and publication of NHS long COVID data.

Despite investment in services, there are reports of [challenges](#) around a growing demand for limited services and inequitable access. In June 2022, the Office for National Statistics (ONS) estimated that approximately [two million people across the UK are suffering from long COVID](#) symptoms such as fatigue and muscle pain, which is double the number reported in May 2021. With only 89 long COVID clinics across the country, treatment is difficult to access with many on waitlists for assessment. There is also inequity in access to long COVID clinics along the lines of socioeconomic status. Despite data that those from the poorest areas are 40 per cent more likely to suffer from long COVID compared to those living in the richest areas, [ONS data for clinic assessments](#) shows they account for only one in five patients.

WORKPLACE ACCOMMODATIONS AND CONDITIONS

What we know and directions forward

In general, the pandemic has led to a changed understanding of work and health. This is particularly the case in essential sectors where frontline workers were at higher risk from workplace outbreaks, which were key sites of transmission during lockdowns and other public health measures.⁴⁹ There is also evidence that the working age population is most impacted by long COVID,⁵⁰ which highlights the importance of policy that addresses the work-related needs of people with the condition.[†]

The literature is clear that prolonged symptoms from COVID-19 will have a significant impact on many people's ability to function at work. Symptoms range in the degree to which they impact people's function, but even relatively mild symptoms may render individuals less able to perform the roles that they previously fulfilled. One international study of long COVID sufferers found that nearly half (45.2 per cent) required a reduced work schedule and more than one-fifth (22.3 per cent) were not working at the time of the survey.⁵¹

Concern is increasing about the potential economic impact of long COVID due to decreased productivity and significant labour market shortages.^{52,53} In line with the burden of acute COVID-19 infection, those individuals who are away from work due to long COVID are thought to disproportionately work in service jobs, including health care and retail.⁵⁴

As with access to health care, the uncertainty of long COVID also comes into play with respect to work. Because it is unknown how long symptoms will persist and what the course of these symptoms will be (e.g., will they improve or worsen), it is difficult for workers to plan for their return to work or to know how long accommodations will be needed.⁵⁵ There is also variation in terms of work-related needs, with some people requiring full-time leave and others needing partial accommodation. Furthermore, some individuals return to work only to experience a flare-up of symptoms,[‡] thus, requiring that they go back on leave.⁵⁶

The work-related impact of persistent COVID-19 symptoms has also been documented, and many individuals describe a lack of understanding from others, including employers and family members, around their inability to work.⁵⁷ The research to-date points to the need for a robust workplace safety net, which includes adequate benefits to cover sick leave, disability benefits, workplace accommodations and flexibilities, not to mention protections to prevent transmission of the virus.⁵⁸

In this regard, people in the workforce need access to adequate sick leave to foster recovery. Most sources contend that employers hold a key responsibility to help workers with their work-related challenges associated with long COVID by taking a flexible and supportive approach to accommodate the individual's particular needs. This could include focusing on accommodations, changing roles, providing reduced work hours, or a flexible return-to-work plan.^{59,60} As indicated, the uncertainty described requires flexibility on the part of the employer with respect to both work accommodation and conditions, and some research places this within a broader COVID-specific workplace policy framework that allows for absences and accommodations for disease prevention.⁶¹

[†] While it is unclear whether as many people will experience long COVID-19 symptoms after infection with the Omicron variant, even a small proportion of the population (e.g., 5%) has the potential to have a significant impact on the workforce given the extremely high rates of infection within the population in Canada (Antonelli et al., 2022).

[‡] This is understood in some areas as representing a condition that is 'episodic' in nature where people experience fluctuating good and ill health, with associated disability (O'Brien et al., 2022).

In addition to accommodating worker's needs, employers have the responsibility to provide other kinds of supports where relevant, such as assistance in accessing financial supports and supports for mental health and emotional needs.⁶² Workplace accommodations will be different if the job can be performed remotely versus in person. For example, some frontline work may be more physically demanding, requiring a different long COVID response from employers. As well, the mental health impacts of returning to a workplace where COVID-19 was contracted in the first place will need consideration in supportive responses to facilitate return to work.

Equity considerations

The fact that the workplace has been a key site where inequities have transpired throughout the pandemic further highlights the need to address worker health. There have been clear inequities in terms of the experiences of low wage, racialized individuals, who are disproportionately represented in frontline work with greater exposure to risks such as high-density spaces, lack of ventilation, or close contact with others.^{63,64,65}

Those individuals who are at higher risk of contracting COVID-19 are also less likely to have job protections such as sick benefits and health insurance, and workers without access to adequate paid leave policies and health-care benefits to address long COVID are more likely to be low income and racialized.^{66,67} Combined with other inequities in access to social and economic resources, lack of benefits to support workers will contribute to long COVID inequities considering the importance of rest in recovery.

Research from the US and elsewhere have highlighted that the lack of protections for frontline workers constitutes a prime example of discriminatory policy, given the disproportionate representation of racialized groups, including immigrants and refugees, in low wage essential industries.⁶⁸ Furthermore, it has been documented that in Canada, workers with disabilities have been disadvantaged compared to workers without a disability with respect to lacking pandemic-related work accommodations that enable them to perform their work duties.⁶⁹

There is a need for policies that start to address the inequitable impact of the pandemic on specific groups in the workforce. This includes protections like paid sick days and health benefits which have the potential to widen or reduce health disparities.⁷⁰ Protections are especially needed for workers in non-standard work arrangements (e.g., gig work). While this kind of work was increasing prior to 2020, the pandemic accelerated the trend, and the area is characterized by a lack of job protections and benefits.⁷¹

Example of a policy response: Denmark Sickness Benefits Programs

A scan of international and Canadian jurisdictions did not uncover description of any structured workplace accommodation or benefit programs that had been specifically designed for those suffering from long COVID. However, some countries expanded existing sickness benefits for people unable to work due to COVID-19, which would benefit those requiring extended sick leave due to long COVID symptoms.

In [Denmark](#), the Salaried Employees Act and most other collective agreements include a provision for employee sickness benefits for a maximum of 22 weeks in a nine month period – covering at least 90 per cent of employees' full salary. Generally, the first 30 days are to be covered by the employer, with municipalities picking up the costs thereafter. This condition was removed from March 2020 to April 2021 following the rise of COVID-19 cases, and the state fully financed sickness benefits for employers, employees, and the self-employed.

Denmark also temporarily extended the length of paid sick leave between March 2020 and November 2021. Those who had exhausted their sickness benefits between March and June 2020 received a continuation of up to four months – this was later further extended until October 2020. Those who exhausted their entitled leave between November 2020 and November 2021 received an additional 3 months of benefits. Eligibility for these sickness benefits was expanded during this time to include those identified to be at-risk of serious or long-term case of COVID-19.

INCOME SUPPORTS

What we know and directions forward

As outlined in the previous section, poor health is not the only consequence of long COVID. Work disruption and reduction in earnings are common experiences for those suffering from long COVID. People report a range in terms of length of absence from work,⁷³ and in some cases, long COVID has significantly impacted people's financial circumstances.⁷⁴ If people have access to income supports, then these are likely to be reduced from previous earnings, and for those with other resources (e.g., savings or other assets), these can become quickly depleted if relied upon for an extended period. Recognizing that workers who are ill from COVID need paid time off work to recover has been widely accepted as an important public health intervention during the pandemic.⁷⁵

In addition to employment benefits, there is a need to ensure access to short and long-term income support programs for people with long COVID. Adequate amounts of income supports that are available for flexible durations to meet the needs of the individual are required. When people are not able to work, they should have access to a range of income support options depending on their situation, whether this is employer or government provided, so that they are not worse-off than before they became ill. People who are not in the labour market when they get sick (e.g., students, those who are unemployed or between jobs), equally need access to decent income programs provided by different levels of government.

Furthermore, there is a need to consider eligibility into existing programs from a long COVID perspective. The uncertainty surrounding the condition comes into play with work, where it is difficult to plan for return to work or know in the short-term, how long accommodation will be needed.⁷⁶ Programs should allow for built-in flexibility in income support programs as well as acceptance of medical uncertainty about how the condition will play out in a person's life (e.g., how long, to what extent).

The World Health Organization recommends the expansion of universal income protection over the life course as part of a broader set of measures to address health inequities and the socioeconomic effects of the pandemic, including long COVID.⁷⁷ These income protections should support those who are temporarily or permanently unable to work. Calls for a universal basic income gained traction throughout the first few years of the pandemic with the realization that existing government programs fall short of providing inclusive financial security during and following emergency situations. Genuine universal basic income programs are unconditional and not time limited.

Equity considerations

It is well known that income is a key determinant of health. Economic security enables people to access adequate housing, food and other necessities to be able to recover from illness and live healthy lives.⁷⁸ We have already seen economic inequities grow over the pandemic,⁸² with stark differences in experiences between those who maintained health and employment and even managed to increase their savings, and those who lost their jobs and continued to struggle in low paid jobs with no benefits, while facing higher relative costs.⁸⁰

Recognizing that workers do not know how long they will be ill, explicit provisions for paid short and longer-term sick leave for front line workers and those with fewer benefits and protections will be needed. In particular, provisions to ensure that those employed in non-standard positions and the gig economy have access to paid sick leave and income benefits⁸¹ will be important to address inequities in experiences of long COVID. The federal government's pandemic income support programs (e.g., Canada Emergency Response Benefit) were important sources of support for those with access to the full benefit and who could not work due to circumstances such as lay-offs or illness during the first two years of the pandemic.^{82,83}

At the same time, adequate income supports should not be conditional or tied to employment. In line with the patterns to-date during the pandemic, people with long COVID on low incomes are likely to suffer greater negative health and economic consequences,⁸⁴ particularly if they are forced to rely on work or existing income benefit programs.

Many are currently struggling with inflation and affordability⁸⁵ but those living on low incomes who were already struggling to get by will be the most negatively impacted by the rising cost of living. For decades, people in Ontario have been living on inadequate social assistance rates that are not fixed to inflation.⁸⁶ In the current climate, the implications of this reality will be even greater. From an equity perspective, the living conditions people with long COVID who rely on social assistance are confined to, cannot support recovery.

The same intersecting factors (e.g., racialization, disability) that shape inequities in accessing the healthcare system are just as relevant in thinking about income inequality. Without responses that provide adequate, stable incomes for people suffering from long COVID, there is a likelihood that health and economic inequities will intensify.

Example of a policy response: Improved disability income support programs

A scan of international policy on long COVID did not uncover any income support programs specific to people with long COVID. Most pandemic emergency income programs introduced by governments have been either stopped entirely or scaled back, and no programs guarantee universal access to both workers and those who are unemployed.

One possible pathway to short or long-term income support for those with disabling symptoms of long COVID is to access existing disability benefit programs. Unfortunately, a lack of clear diagnostic criteria and recognition of long COVID as a potentially disabling condition presents significant barriers to those looking to qualify.

The U.S. Department of Health and Human Services recently [provided guidance](#) on acknowledging long COVID as a disability under federal civil rights laws. However, this does not guarantee access to federal benefit programs such as the Social Security Disability Insurance (SSDI), which has [strict qualifying criteria](#) that includes providing proof that the disability will continue for 12 months.

Other comparable disability income programs face [similar challenges](#) around income level and conditional eligibility requirements. For example, most income support programs are linked to exit

from, or return to, work requirements. [Research](#) finds that social assistance programs are failing to maintain health for marginalized populations in high income countries.

The Ontario Disability Support Program is one of several pre-pandemic income programs available to people living with disabilities in the Greater Toronto Area. As with federal disability support programs, significant challenges have been documented around access to these programs and their design. There are longstanding barriers to access to the benefit for people with conditions, like long COVID, that lack a single standardized diagnostic test, and therefore require a clinical diagnosis. The ODSP benefit, at about \$1169/month for a single person, provides a level of income well below the poverty line. Wellesley Institute's work on income and health encourages moving from [surviving to thriving](#) in thinking about supporting well-being through adequate income levels, and this should account for the additional costs associated with living a healthy life with a disability.

Reform of existing disability income support programs is needed to adequately support people with long COVID. These programs should be available to everyone who needs them and offer a level of income that enables access to healthy living conditions.

COMMUNITY-BASED CARE AND SUPPORTS

What we know and directions forward

Although it is not discussed in-depth in the literature, research on the experiences of people with long COVID suggests that daily activities like self-care, housework, cleaning, care for others, can be difficult.^{87,88} In these situations, people are likely to rely heavily on family and friends if this kind of support is available, and private paid domestic services if they can afford it. If they do not have the resources for private support, then they may require access to existing community care programs.⁸⁹

Responses to long COVID need to address how to provide at-home supports for people so they can live independently and recover in the community. In addition to the workplace protections and flexibilities discussed earlier in this report, these provisions are also required for family members who provide care to people suffering from long COVID.⁹⁰ The introduction of a universal basic income mentioned above would address the need for income supports for unpaid caregivers. Where a person does not have support from family to fulfil basic needs, they should have access to adequate community care services.

Once again, the pandemic has highlighted substantial challenges facing the home and community care sector in Canada, including significantly reduced capacity due to worker turnover and labour shortages.⁹¹ Sector issues, such as wage parity, will need to be addressed to adequately respond to the homecare needs of people living with long COVID, in addition to the increasing aging population requiring care.

The experience of those living with long COVID has been described by many as socially isolating, impacting their sense of self and well-being.⁹² Many people have found important support in online community groups to share information about experiences and helpful knowledge about the condition. For those who are socially isolated or disconnected from community or lived experience groups, it will be important to provide resources for at-home and social supports.

Equity considerations

Maintaining household and other duties may be even more difficult with individuals with low incomes and facing related inequities, who lack resources and networks to gain support with daily living.⁹³ Already, 30 per cent of households in Canada that require home care pay entirely out-of-pocket, providing opportunities for greater access to those who can afford private supports, and contributing to access inequities (e.g., longer wait times) related to income and other social determinants of health.⁹⁴

As well, it is disproportionately women who are responsible for unpaid care work, and this has the potential to significantly interfere with their position in the workforce and, consequently, their income.⁹⁵ The pandemic has shed a light on the undervaluing of paid and unpaid caregivers in society through lack of appropriate wages, protections and benefits.⁹⁶ In fact, those who provide informal care in society are also in need of health and mental health services, and economic and social supports to enable them to fulfil these roles.⁹⁷ Again, lack of access to economic resources should not unfairly disadvantage some groups in their recovery.

The burden for providing care to people with ongoing symptoms should not fall on unpaid labourers without the necessary financial (and other) support from governments and private employers. Without these supports to provide care to people in the community there is once again a risk that existing inequities (across income, race, gender, ability) will be exacerbated.

Example of a policy response: Canada Recovery Caregiving Benefit (CRCB)

The [Canada Recovery Caregiving Benefit \(CRCB\)](#) was introduced in September 2020 following the phasing out of the Canada Emergency Response Benefit (CERB). It provided income support to employed and self-employed individuals who were unable to work at least 50 per cent of their scheduled work week because they were providing supervised care for a family member. The benefit was available to those who needed to care for family members who were sick with COVID-19 or at risk of serious health complications if they contracted COVID-19.

There were restrictions that limited access to the program. To qualify, applicants could not be receiving any other form of federal pandemic response benefits, workers' compensation, social assistance, or employment insurance benefits. The program was extended since the initial benefit period from a maximum of 26 weeks to a maximum of 44 weeks. If eligible, the caregiver received \$500 for each one-week period. The CRCB ended on May 7, 2022 and was open to retroactive applications until July 7, 2022.

Although the CRCB was not targeted towards those with long COVID, it was a unique program that recognized the impact of COVID-19 on family caregivers and the value of care work through targeted financial support. The continuation and expansion of income support programs like CRCB, from either the provincial or federal government, along with other health and social supports, is needed to address the complex needs of those who have caregiving responsibilities. A future program would have to account for the complexities of long COVID, be easy to access, and provide enough financial and other support to allow caregivers to provide the care that is needed to their loved ones.

CONCLUSION

As research attempts to uncover the medical and biological realities of long COVID, there is a portion of the population who require healthcare services and other social and economic supports now. This paper provides a rapid scan of the literature to identify some key policy areas – access to healthcare services, workplace accommodations and conditions, income supports, and community-based care and supports – for decision-makers to move forward with supporting people living with long COVID. It is not meant to be exhaustive but is a starting point for thinking about long COVID inequities and responses.

This policy work is a preface to forthcoming research from the Wellesley Institute that will expand the analysis through the perspective of people struggling with ongoing COVID-19 symptoms in the Greater Toronto Area. The empirical research will provide depth by analyzing their experiences in different social realms, including the areas discussed here.

There is a need to prepare for a range of experiences with respect to impact of long COVID on people's ability to function and the corresponding need for supports. In this regard, an equity lens should also be prioritized to remediate heightened suffering of people with long COVID symptoms who face inequities in access to resources and material conditions. Inequities in long COVID can stem from different pathways, including acquiring COVID-19 in the first place, accessing healthcare services, economic and social supports, and so on.

Finally, in the face of the many uncertainties about the condition – the extent to which recent variants will cause prolonged symptoms, how re-infection with the virus shapes risk of ongoing symptoms – we should, as a society, take precautions to minimize potentially serious risks. Public health measures to reduce transmission of the virus (masking, physical distancing, vaccination) are effective in preventing acute infections and by extension will reduce long COVID risk. All levels of government, employers and others need to facilitate these practices.

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