# The Work Experiences of People with Long COVID in the GTA

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#### **BACKGROUND**

Recent calculations suggest that as many as 1.4 million adults in Canada will experience persistent symptoms following infection with COVID-19 lasting three months or longer. The type and severity of symptoms experienced with long COVID varies considerably among individuals, with some reporting debilitating symptoms including impairment and reduced function.

A previous paper by Wellesley Institute on the healthcare experiences of people with long COVID in the Greater Toronto Area (GTA), raised the importance of healthcare providers in supporting workers to access benefits, sick leave and income supports when needed. Reviews of qualitative research on long COVID have also identified financial hardship as a challenge for many people with long COVID.<sup>3</sup>

The prevalence of long COVID is greatest in the working-age population (those aged 18 to 65) compared to other age groups.<sup>4</sup> Although there is uncertainty around the exact impact of long COVID on the labour force at the population level, it is known that long COVID symptoms have the potential to interfere with a person's ability to work.<sup>5</sup> Research to-date suggests that many people with long COVID require workplace accommodation, extended leaves from work or experience loss of employment.<sup>6,7,8,9,10</sup> A qualitative study on 145 workers recovering from COVID-19 in the UK found that only 15 per cent had managed to fully return to work.<sup>11</sup>

Worker absenteeism due to persistent COVID-19 related symptoms poses a major challenge to employers and the labour market more generally. <sup>12,13,14,15</sup> Estimates from the US in 2022 suggest that of the 16 million working age adults with long COVID, between 2 and 4 million are not working due to their condition. <sup>16</sup> The economic impact in that country has been estimated at as much as \$200 billion per year. <sup>17</sup>

Despite these projections, research on the experiences of people with long COVID suggest that they are not receiving the support they need from employers. <sup>18</sup> People living with long COVID have also reported limited workplace understanding of the impact of their symptoms in limiting their ability to work. <sup>19</sup> At the same time, the ability to take time to rest or pace oneself during activities such as work has been identified as an important element of recovery from long COVID. <sup>20,21</sup>

There continues to be considerable gaps in knowledge of the work experiences of people living with long COVID, and this has not been well-documented in Ontario or the GTA. This paper reports on the experiences of a group of people with–or caring for someone with–long COVID in the GTA. The research explored the challenges that participants faced in continuing to work with persistent symptoms, and considered the variations of support from workplaces. These experiences are analyzed to consider what they mean for employers, different levels of government, and decision makers in their actions to address long COVID-19 in the workplace.

#### **METHODS**

This paper focuses on the work experiences of people with long COVID. Qualitative, semistructured interviews were conducted to explore the experiences and perspectives of people who self-identified as having ongoing symptoms from COVID-19 that had lasted three months or longer and family members or friends providing support to people with ongoing symptoms. A three-month duration of symptoms following acute COVID-19 infection was chosen to align with the World Health Organization's post COVID-19 definition.<sup>22</sup>

Participants were recruited through community organizations in the GTA and online long COVID community groups. They were included in the sample if they were 18 years of age or older and lived in the GTA. A purposive sampling strategy was used to maximize diverse representation of participants based on self-identified gender, employment status, income, ethnic and racial identity, or age.<sup>23</sup>

Interviews were conducted from March 2022 to September 2022. They were conducted in English via telephone or video call (e.g., Zoom). Interviews ranged from 30 to 94 minutes in length. Interviews were audio-recorded and transcribed verbatim.<sup>24</sup>

Interviews focused on participant's experiences seeking treatment and support for long COVID within the health care system and related to work and other aspects of social participation (e.g., social connection, care for children and other dependents). Inquiry during the interviews also explored potential supports that had been or would be helpful in these areas.

Interview transcripts were analyzed by the project team in NVivo using a thematic analysis approach. Analysis involved an inductive technique where emerging codes were generated using a systematic approach and derived directly from the data. A coding matrix was developed which comprised a list of focused thematic codes. The preliminary list and observations were discussed within the project team and thematic codes were revised and then applied across all transcripts. As analysis progressed codes were gathered into broader themes which were then organized and refined with ongoing engagement with the data.

Ethics approval for the research was granted by the Toronto Metropolitan University Research Ethics Board in February 2022 (REB # 2021-548).

#### **RESULTS**

The sample included 18 participants in total. Out of the 18 participants, 14 were people living with long COVID and 4 were caregivers who were family or friends providing support to people with the condition.

**Table 1** summarizes some key sociodemographic characteristics of the sample. Most participants identified as women. Half of the sample was in their 20s and 30s, and the other half aged 40 years and older. All participants with long COVID were working aged. All but one of the caregiver participants were working at the time of data collection. Eight participants self-identified as South Asian or Indo-Caribbean, and seven identified as White. One participant each identified as Latin American, West Asian and Caribbean.

Half the participants living with long COVID were working, with five participants employed in full-time positions and two in part-time positions. Four participants were on sick leave from work, and one of those participants had just started gradual return to work.

Three of the four participants on leave were employed full-time and in the top income bracket for the sample (\$60,000-80,000+/year). The remaining three participants were unemployed or students. Of these three, two were women in their 30s who had been employed in a contract position when they had become sick with COVID-19 and had not been able to return to work.

Among those who reported, the household income ranged from under \$16,900 to over \$80,000. Four participants reported household incomes under \$35,000, four reported between \$35,000 and \$60,000, four reported between \$60,000 and \$80,000, and one reported \$80,000 or higher. The number of household members supported by the reported income ranged from one to five, with the average of two and half.

Table 1: Sociodemographic characteristics

Sociodemographic factor (self-identified)	Sample breakdown, N=18 (#) (%)
Gender	Women (16) (89) Men (2) (11)
Age	20s (4) (22) 30s (5) (28) 40s (2) (11) 50s (3) (17) 60s (4) (22)
Ethnic/racial identity	South Asian/Indo-Caribbean (8) (44) White (7) (39) Latin American (1) (6) West Asian (1) (6) Caribbean (1) (6)
Born in Canada	Yes (11) (61) No (7) (39)
Employment status <sup>1</sup>	Full-time (5) (36) Part-time (2) (14) Unemployed (2) (14) Student (1) (7) Employed, but on-leave (4) (29)
Household income	Less than \$35,000 (4) (22) \$35,000-\$60,000 (4) (22) \$60,000-\$80,000 (4) (22) More than \$80,000 (1) (6) Not reported (5) (28)

Work was a key area of concern for many participants who found that long COVID symptoms interfered with their ability to perform their previous functions. There was variation across the sample in the degree to which long COVID interfered with work duties. Accommodations from workplaces and other supports, such as access to sick leave and benefits, were important for allowing them to manage their symptoms and facilitating recovery.

<sup>&</sup>lt;sup>1</sup> Includes participants with long COVID only; caregivers reported employment status for their family/friend.

#### **Experiences of working with long COVID symptoms**

Many participants with long COVID had difficulty performing duties at work with ongoing symptoms. Some described not being able to perform their regular work duties due to problems with physical and mental function. One participant described the challenges she faced leading a team,

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"I was leading a team [at work]. I didn't feel like I was doing anything very well...I felt so stupid. I think my executive functioning was not operating in the same capacity; I was not articulate; I was searching for words all the time...Even the way that I responded to things, like, both cognitively and emotionally, just felt off. I did not feel myself..."

(L04)

The participant described numerous long COVID symptoms that she was struggling to manage at work, including debilitating fatigue, chest pain, a sore throat, migraines, brain fog, and difficulty recalling words. Other participants echoed that the combined effect of physical and cognitive symptoms made work challenging. One person who was also experiencing significant physical symptoms found the cognitive limitations to be particularly challenging at work,

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"The fatigue has always been pretty intense...what was a lot more difficult for me to see and to accept was that I have some cognitive limitations...it was hard for me to get through the workday, and so I was kind of trying to hide it from my boss – like, take breaks in the day when I wasn't too busy – but I noticed that it was really hard to concentrate and pay attention, and learning new things, and...then sometimes I'd notice that weakness – [it was] extreme."

(L05)

Other participants described struggling with intermittent symptoms at work, where they would improve only to experience a recurrence of symptoms at a later time,



"This [is] very much a messing with your mind kind of illness because I would start to think I was better, and I would try to go back to [work]...and then it would get worse again...I had shortness of breath with just very small amounts of walking...and then I would start to feel better...and I'd tell everyone 'I'm getting over it,' and then I'd eat my words two days later. I think my workplace was a little confused by that..."

(L06)

A caregiver participant explained that her friend with long COVID had been unable to work due to a range of unpredictable symptoms including heart function, memory impairment and a pre-existing neurological disorder that had worsened,

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"[My friend] has not been able to go back to work because they [have]...a lot of memory issues...
The other thing that has worsened is their heart function, so things like shortness of breath, as well as palpitations...and then the other thing is...[they] already had a [neurological] disorder, and so it worsened...and a lot of people don't have a warning [for the symptoms from the disorder]...when they're gonna get it, and so to be able to work, especially in a job that's physically demanding, that requires you to be on your feet, not sitting in an office, it's really hard to be able to do that."

(C01)

Most participants found symptoms difficult to manage in their various work roles. Several described employers who were "confused" by the inconsistency of their symptoms, especially when they seemed to improve but subsequently had to take time off.

While some participants in the study described attempts to manage symptoms at work, others explained that their symptoms prevented them from working. One person who was unemployed at the time she contracted COVID-19 felt that the ongoing symptoms she was experiencing would have made working very difficult,



"I had less energy than I had previous to COVID, and I would become breathless, you know, climbing stairs or going up a steep hill...and then the fatigue, and then also breathlessness and heart palpitations, I was starting to notice more and more, and on top of the fatigue, and then I was having constant headaches...[that] didn't go away...I mean if I had been working, would I ever have had a lot of trouble."

(L07)

L07 hoped to enter the workforce in the near future but was uncertain about whether her symptoms would permit this. Another participant who had mild respiratory symptoms and loss of smell continued to work fairly easily in a hybrid work arrangement. On the other hand, her mother-in-law who also experienced prolonged symptoms following illness with COVID-19, had not been able to continue working,



"She feels that there is some changes in her body, and she gets tired easily...she was working twelve hour shifts, but now she works for some time and she feels tired, and she needs to take a pill to just cope with that tiredness and fatigue...she's not going to work...but even in the house, if she works for about an hour or two she would just get tired, and then she would have to sleep for 5-6 hours, or maybe take a pill and then do the rest of the things. So, I just see her taking medication almost every day."

(L11)

Some participants who had been on short-term leave struggled returning to work with continued symptoms. One who was returning to work was worried about managing the stress of providing support to people in crisis, in addition to her ongoing headaches and respiratory problems,



"So people who are going through [crisis] that call in for help and need support...I'm already having these headaches, and, then, you know, I am an empathic type of person...[so if] somebody calls in about a situation, then I don't want to get my head hurting. My body right now is just not good, and I want to rest, right, because I need to slow down...So, if work is stressing me, then that can be an issue...And even when we've been talking right now [during the research interview], like my lungs are feeling a bit tight."

(L13)

Most study participants described the impact of long COVID symptoms on their ability to work. Many described the combination of physical and cognitive challenges and the unpredictability of their symptoms as difficult to manage while performing their regular job roles. Several were unable to work due to long COVID. In general, participants who worked in "frontline" positions, which were physically demanding or where they had to deal with people directly, faced even greater challenges.

#### Workplace support for symptom management and recovery

Participants' experiences varied in terms of how much support they received from their employers. Some illustrated how their work environments promoted the management of symptoms and rest and recovery from long COVID. Others described struggling with the job demands, with little flexibility or practical and emotional support and limited access to benefits or time off work.

#### Flexible work environments and accommodations

In general, participants with fewer options or flexibility to reorganize their work or modify roles were those working in-person or directly with the public. Several participants in frontline positions explained that they lacked the flexibility to manage symptoms. In-person attendance and related pressures (e.g., stress from commutes) were described as negatively impacting their ability to manage symptoms,



"And it's been tough...my commute to work is about half an hour...If my migraine starts really bad in the morning, it's tough to do it..."

(L10)

Several participants who were required to work in-person, described anxiety about the ongoing risk of getting re-infected with the virus through close contact with others,



"[Work] is in-person, but it's very uncomfortable...you see people sneezing and coughing. It does make you kind of anxious...And even a little bit of panic that comes with going in and seeing people show symptoms...especially with children because they're so touchy...but it's also something that you can't raise a concern about at work because it's like, that's your job."

(L02)

Other participants who were in frontline positions, working directly with people who at times required high levels of physical support, described the challenges of distancing themselves from others throughout their workday.

At least three frontline workers reported that they had originally contracted COVID-19 at work and several others were unsure or had contracted the virus through family members who worked in frontline positions. Most of these participants described the emotional toll of potential exposures at work. They were uncertain about what would happen if they were to become re-infected and the work conditions were contradictory to what they needed for recovery.

Another participant was working directly with vulnerable clients in a community organization. In this position, she did not have predictable shifts and earned a relatively low income (just above the poverty line). The participant did not feel that she could discuss workplace accommodations to better manage her respiratory symptoms with her employer because of the precarity of her position,



"I don't want to take on anything else [other work or opportunities] because I want to be available. So, it's going to be a few months of not knowing when, how and where [my shifts are scheduled], but I'm hoping by the end of this, I will end up in a position [with more predictability], or as a relief worker which is still on call, but you have certain shifts, and then you can take on other shifts, but they're not gonna hire me 'til I have some experience, right, so I have to do this, I have no choice...[I'm at their] beck and call...I don't want to have them not employ me. I just have to sort of suck it up, right?"

(L14)

L14 experienced relatively little control over her work environment and was reluctant to raise issues related to her long COVID symptoms for fear that she would lose her position. These examples demonstrate the lack of flexibility experienced by many participants in this study in terms of workplaces accommodating their needs around long COVID.

In contrast, other participants described the ways they were able to manage their symptoms at work through informal mechanisms and employers who accommodated changes to roles or work organization (e.g., hours). One participant described her struggles to work full days before going on sick leave,

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"I did notice that I was pretty tired through the workday, but...you know, I just thought I'd push through and it'll just be another week or so, and I managed it by taking breaks as much as I could, but I was also quite open with my colleagues, saying, 'Hey, I'm still really tired after having COVID', and they were really supportive – you know, if I had to sign off a bit early, or somebody covered for me once when someone started a meeting at 5 pm...I was already lying down in a dark room, and someone just made up a lie for me (laughs) about where I was, and... I appreciated that because I had a lot of support."

(L05)

This participant described a greater capacity to manage her symptoms because she did not interact directly with clients and she was able to work remotely. Other participants similarly described being able to take breaks when needed, skip the occasional meeting when they were feeling unwell, and having the flexibility to regularly work from home where it was often easier to manage symptoms.

Another participant who had been on long-term leave due to long COVID described his gradual return-to-work and the support of his employer,

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"So, I finally went back to work...and they had me on very light duties, and two hour shifts at the beginning, and they were slowly trying to build up my strength. So...I just went to the doctor the other day, and I'm up to twenty-four hours a week...because every time I work two days in a row, I'm exhausted...so it's been a, you know, a slow going process."

(L08)

The participant described his employer as providing a lot of support during his leave and return-to-work. He had access to paid leave when he was unable to work and benefits, such as mental health supports, which helped him considerably in managing his symptoms.

#### Access to paid sick leave

While some participants were able to manage their symptoms at work, others were not in a position to adapt their work duties or seek accommodations, or were unable to work despite the flexibility of their employers. Some participants were able to take short- or long-term sick leaves, whereas others continued to work out of necessity.

One participant who worked directly with people and did not have access to paid sick leave explained that she could not afford to take time off to rest and improve,

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"[E]ven if we have a doctor's note or something, we don't get paid if we're sick, and [in our line of work, we]don't get paid a whole lot [anyway]...So, the people who do it...they need to go to work because, that's paying their bills, for sure, and it requires long hours."

(L02)

Other participants were in precarious work situations, such as being employed in contract or on-call positions. One person (L06) was completing a professional training requirement when she acquired long COVID. She had been unable to work towards the end of her training and continued to be ill with severe symptoms. As a result, she had not re-entered the workforce and without substantial improvement in her health she did not foresee being able to work in the future.

Some participants described more mixed experiences. One person who was returning from a short leave from work was worried about being able to perform her role with persistent symptoms, but felt that requesting additional time off was not an option,

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"[My employer] understands to some extent...if it's just for short-term [leave from work or accommodation]...but if it becomes long-term, then I will be needing a doctor's document to prove that I am actually experiencing this and that I need that support ...You know, if you can't work then it is a problem...eventually someone will say 'This is not working."

(L13)

Several participants similarly felt that they would risk losing their jobs if they took more than a few weeks off work due to long COVID.

Many participants who described supportive work environments that provided accommodations also had access to short- and longer-term sick leave when needed. As one participant who had been off work for three weeks explained,



"I came to the decision to go on sick leave. I have the option of short-term disability with a reduced pay at 75%, so I had a lot of support. I just called my doctor, and I told him what's going on, and I said, 'I need to take a break.'"

(L05)

This participant had the option of extending sick leave if necessary, although she found the ongoing process of applying for an extended sick leave with her physician to be very stressful.

Even some participants in relatively secure work positions with a lot of flexibility to address long COVID experienced challenges accessing longer-term sick leave. One person had difficulty once he tried to transition from short- to a longer-term leave. The insurance company arranged for him to attend a private long COVID clinic to facilitate his return to work and claimed that his medical records did not display evidence of the need for extended leave,



"When I was off on the short-term part of it, {the insurance company} was okay with it all, but as soon as you go from short-term to long-term, then they put this huge amount of pressure on me to go back to work. I actually had a huge fight with a guy on the phone, and I said to him, 'My doctor is not prepared for me to go back to work yet, and even though your {Post COVID clinic} guy says, 'Hey, he can walk around the building', whatever, I can't work yet, pal, you don't understand. Believe me, I want to be there more than anybody'...Anyway, at the end of the day, I had to appeal the decision, and after them talking to my doctor, they okayed me to go on long-term disability."

(L08)

The insurance company tried to prevent him from accessing his benefit because of the intermittent nature of his symptoms where he was sometimes able to perform physical tasks that did not align with their assumptions about disability. After working with his family physician to advocate for access to the benefits, he was granted long-term sick leave for eleven months so that he could properly recover. At the time of the interview, he was in the process of a gradual return to work.

There were variations in participants being able to access short- and long-term sick leave benefits, but all participants felt these were important options to promote recovery. While approximately half the sample had some access to sick leave, most of these participants described some level of stress around having to apply for leaves.

Participants who described being supported to take time off work, gradually return to work when ready, or who had accommodations in place when they did return, had often attained seniority in their positions and were earning higher incomes to match. Several participants did not have any significant concerns about working with symptoms which were relatively mild compared to the rest of the sample.

#### **Practical and emotional supports**

Participants had different experiences in terms of the flexibility of workplaces and accommodations provided by employers. Similarly, descriptions varied in terms of the extent to which participants felt supported emotionally and practically within the workplace. Some participants felt especially supported in communications with employers and supervisors and in their corresponding responses,



"I sent [my boss] an email, and I said, 'Listen, I'm really struggling, and I'd like to have a conversation as soon as you're available. I just told her what's going on – like, the post-COVID fatigue and it's not getting better, it's getting really hard to get through the workday. So, I got support really quickly...it was a bit embarrassing to sort of say I can't handle my job. I'm at a senior level..."

(L05)

Another participant described feeling supported at work and attributed this partly to her security and tenure,



"I've been very fortunate that the company that I work with, and because of my seniority, that they've been very supportive, and they have worked around me...Now, am I at my best? Not at all. You know, and obviously that's very frustrating. I don't like operating sub-par, but they have never made me feel inadequate or pressured to contribute differently."

(L04)

Participants who felt they were in supportive work environments described supervisors who listened, were empathetic, and provided practical solutions such as lessening workloads. Other participants described some emotional and practical support from employers despite a lack of benefits such as access to long-term sick leave. One person who worked in frontline positions at two different organizations had been able to take a paid short-term leave because she was unable to perform physical tasks. She was required to return to work despite continuing to struggle with symptoms like shortness of breath. Although she did not have access to longer term leave, she described her employer at one of the organizations as supportive of her,



"At work I was weak, so [my] workplace, they didn't give me that much hard work. They said, 'Whatever you can do, you can do. Don't push yourself.'"
(L09)

Despite the support received by some, several participants described struggling with shame or diminished self-worth because they were not able to perform work and other duties that they were before they got sick. They described wondering what their supervisors were "really thinking" or employers who were "confused" by the presentation of their symptoms. Some described attempts to hide symptoms from others at work and "sneaking" breaks during the day. During the research interview one participant explained that it was his first extended work leave in what seemed like an attempt to distinguish himself from employees who were frequently absent from work, "I never miss work. You know, I've always been...considered a very good employee, manager or whatever." (L08)

These experiences highlight the general lack of understanding about chronic health conditions, such as long COVID, in workplace cultures. Participants highlighted the need for enhanced awareness about how long COVID impacts workers and supportive responses from employers and others,



"People who are at work, or trying to get back to work – they need all kinds of accommodations... [from employers and insurance companies] that actually understand what it is they're suffering from 'cause so many people now are being made to go back to work in conditions that they can't manage because it's not understood that long COVID is a disease of episodic nature – one day you might be able to do the job, where, you know, you're running around...doing whatever you can. And then in two days you might not be able to do that same job...So, [employers and insurance companies] are saying, 'Well, you did it two days ago...'"

(L12)

Other participants described struggling at work and did not feel that their workplace was supportive of their condition, including those who were hesitant to raise the issue in the first place. Many of these participants were in more precarious positions where they had little seniority, less flexibility in their roles, and greater worry about finances.

#### Access to additional benefits

Access to supports like extended healthcare coverage or workplace mental health programs through work were important additional benefits for some participants. Most participants with extended healthcare benefits through work accessed services to help manage their condition. For example, one person described access to workplace mental health supports as important for managing his anxiety from long COVID,



"Well, my doctor set up one, and we at {name of workplace} have a [counselling program for] anxiety that they provide workers for whatever stress, and there's, I think, six or eight...one hour sessions – and I used them all. So, I actually had two different therapists calling me at the same time...Which was good because I wasn't sleeping very good; I was stressed about never getting better, and I was just not good."

(L08)

Several participants pointed out that access to services like acupuncture, massage, and counseling through work were important non-pharmacologic sources of support for coping with symptoms,



"I try to do some meditation and mindfulness first, to see if that will help, before I take the pills, right, I see if that will work to help...I mean I do have some coverage for mental health supports, massage and other things through work, so that helps."

(L13)

Some participants who did not have access to health services through work programs were able to pay out of pocket for these,



"And then I also have used a functional medicine doctor...so I paid out of pocket for that...if you're lucky enough to have, you know, healthcare insurance through work - or additional healthcare insurance, you know, maybe some of your insurance plan might pay for part of it, but that was a very costly endeavor, as well, but very helpful." (L04)

Participants who were able to access extended health services such as physiotherapy, acupuncture, or counselling found these to be very helpful in facilitating the management of their symptoms.

For those working in lower paying jobs and without extended benefits through work these additional health supports were not available to them. One participant who was caring for her young children when she became ill felt that access to extended health benefits would have been helpful,



"I mean, [psychological support] is not something that's especially in our budget, so it's not something I've accessed...we don't have [health benefits through work], so that makes a difference. And even having benefits, I mean, there's other things, like I would probably explore more acupuncture or go for a massage or some of those things just to...help with the symptoms. Yeah, from my understanding, physio can be really helpful too."

(L07)

Generally, participants facing greater precarity generally lacked paid sick leave and other benefits. Some of these participants detailed using other strategies to cope with their symptoms such as frequent use of non-prescription medication to address pain or meditation and mindfulness practices.

#### Impact of inability to work

The financial impact of not being able to work was very stressful for some participants. One participant who had contracted COVID early on in the pandemic did not have access to work leave. She described the difficulty she experienced accessing government benefit programs,



"I got totally messed up with the [Employment Insurance Sickness] benefits...so at one point I didn't get benefits for three months...so, I finally got them, and I was like a week or two into them, and then they called me and told me that they'd cancelled them, so anyway, I went without money for, like, four months, and then I finally went onto CERB [Canadian Emergency Response Benefit], but I feel like I was really lucky that I got COVID in the very beginning because I was able to get those benefits and not have to worry about working, so I could rest, and this is a luxury that not everybody has."

(L12)

This quote highlights challenges around applying for income support programs for people who are unable to work and require rest as part of their recovery. Although it was a difficult time financially, she managed to transition into another relatively well-paid position with greater flexibility (e.g., in terms of choosing her work hours and having the freedom to turn down shifts if she was unwell) after CERB was no longer available. Most participants in this study were not able to pivot so easily to gain opportunities in a different field or position.

A student with ongoing respiratory problems from COVID-19 was living with her parents and siblings at the time of the interview. She described the stress experienced by her father, suffering from similar long COVID symptoms, who was self-employed in a sales position and lacked benefits and a safety net,



"[My Dad] was definitely stressed because, he doesn't have a monthly salary. It's like what he works, that's what he's earning, and so, because he couldn't work for a very long time, he was very stressed, and once he was feeling better, he started to work, double the time that he used to work. Like, for him it was a bit more hard...he got very tired from working...I think [during the time he was unable to work]...he was getting the sickness recovery benefit."

(L03)

As these examples highlight, government benefits like CERB (and the Canada Recovery Benefit program which preceded it) which were more readily accessible at the earlier stages of the pandemic were important sources of support for those who could access them.

Although caregiver participants were not able to comment in-depth on the work experiences of their friends and family, three reported that their family or friends were unable to work due to long COVID symptoms. Of these, two were responsible for dependent children and struggling to make ends meet. In this context one caregiver whose friend with long COVID was receiving ODSP described the inadequacies of longer-term financial supports provided by government,



"The biggest thing is the fact that—it's affecting their ability to work—I think that's the biggest thing. They want to go back to work. They're eager to go back to work, and I think that's something that they're struggling with...I think finances is a big issue...seeking disability support [ODSP]...it's just not enough to sustain the cost of living in Toronto or even outside of Toronto, right, it's well below the poverty line..."

(C01)

Another caregiver described her sister's experience with long COVID. She had been on leave but as a single parent without financial security she was having to return to work to earn an income,



"I think she thought if she could stay home and not work and she had enough money to take care of the kids, but I don't know if that is possible, but she's still surviving... it would be better for her if she could just stay home because she's still...like, since the COVID her, she's not the same. Like, she's become so vulnerable. She's weak; she doesn't have the energy to work."

(C04)

Caregiver participants described the economic stress that their friends and family faced because they were not working due to long COVID. In comparison, another participant who was supported with paid time off described how important it was for his recovery,

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"Since I have been on the long-term [disability leave], [work has] been wonderful...They're working with me, hand-in-hand...They thought I would have been back to work full-time by now. It was a three month progression thing that they had me on, and it's just slower than expected, so to speak, but that's where we are now...You know, at least I had the financial part of it not to worry about. You know, if you added that burden to it, my God, it wouldn't be fun. It wasn't fun as it is, you know...But if you didn't [have an income or financial security], boy, that would be a tough go for people...I can't imagine having to work at wherever...making hardly any money..."

(L08)

Most participants who continued to work commented on general affordability concerns due to the rising cost of living, specifically struggling with food and transportation costs. Participants who described greater financial security and resources had better access to a range of health enhancing supports. Furthermore, economic support from employers for time off for rest when needed was also a benefit for some.

#### **DISCUSSION**

This research explores the work-related experiences of people living with long COVID in the GTA. The results illustrate how the sometimes unpredictable symptoms play out in participants' work experiences. Many described struggling to cope with symptoms while performing regular work duties. Their descriptions included dealing with extreme fatigue, diminished cognitive capacity and other symptoms that prevented them from performing typical roles at work. As well, many described how the variability of symptoms made it difficult to maintain consistent work, plan for workplace accommodations and was a source of confusion for some employers.

Some participants were afforded considerable flexibility in the workplace for managing symptoms, including the choice of remote work and being able to modify roles when needed. Participants also described benefits provided in supportive work environments such as extended healthcare coverage for access to services like massage, counselling, and physiotherapy to support treatment and symptom management. Several participants were also able to take paid short- and long-term leave from work to facilitate rest and recovery.

In contrast, most other participants experienced relatively little flexibility at work. This was particularly reflective of the experience of front-line workers who had shorter employment tenure and were without other protections such as sick days or longer-term sick leave. Frontline workers also described anxieties around greater potential for viral transmission at work because they did not know how re-infection with COVID-19 might impact their symptoms.

These findings reflect the experiences of a group of working-age people with, and caring for someone with, long COVID in the GTA. Despite a growing body of research on the health experiences of people with long COVID, there has been comparatively little qualitative research focusing on work experiences. Nevertheless, several sources draw attention to the potential impact of long COVID on the labour force in various jurisdictions. <sup>25,26,27,28</sup>

The findings in this paper reinforce the ways that work conditions make up a key determinant of health for people with long COVID in the GTA.<sup>29,30</sup> Action taken by employers to support and respond to the needs of those with long COVID can help to mitigate the harmful impacts of long COVID on workers. This research raises questions about what long COVID means for the workplace, including necessary responses from employers and other parties.

Study findings also suggest that there is an opportunity to increase awareness of the impact of symptoms on people at work, and how employers can respond to the needs of workers with long COVID. Canadian research indicates that employers and insurers struggle with the uncertainty around the underlying cause, treatment, and trajectory of long COVID, and recommend education and other measures to address awareness and appropriate supportive responses.<sup>31</sup>

Other research has similarly documented feelings of shame around challenges working for people with long COVID, including attempts to hide difficulties with tasks. <sup>32,33</sup> One study found that people who are not working due to long COVID report experiencing greater stigma than others with the condition. <sup>34</sup> Experiences of stigma can have major implications for quality of life and wellbeing and sense of identity, and act as a barrier to seeking treatment and accommodations. <sup>35</sup> Education efforts to increase awareness about the responsibility of employers to support workers with long COVID may also be helpful in reducing stigma around disability and work.

Researchers and others focusing on workers recovering from COVID-19 have also started to detail the importance of accommodations by employers and guidance for return to work. <sup>36,37,38,39,40,41</sup> In some instances, employer responses and accommodations that focus on financial supports and accommodations have been explicitly identified (e.g., payment for alternative transportation costs for commutes). <sup>42</sup> Emerging evidence suggests that workers with long COVID will have better outcomes in their return to work if they have early access to rehabilitation services and accommodations (e.g., modified roles). <sup>43</sup>

Examples of return-to-work accommodations include: providing conditions to allow workers to self-manage symptoms; flexible return to work plans and work arrangements (e.g., hours); accommodations for changed roles; practical and emotional support for employers; and policies that allow adequate leave for sickness.<sup>44</sup>

This research indicates that workers with long COVID would benefit from consistent access to short-term and long-term sick leave. Since early on in the pandemic it has been demonstrated that increased access to flexible, paid sick days and leave is crucial for promoting health if people are unable to work. This is even more the case since the inability to rest in the early weeks after infection with COVID-19 is a risk factor for long COVID. Although understanding is limited in Ontario and Canada, some have documented difficulties for those with long COVID in accessing benefits through various government programs and other. 47,48,49,50

The findings from this qualitative research raise important questions about how work has the potential to worsen existing COVID-19 and long COVID inequities. While most participants in this study experienced challenges at work, some had time off to recover whereas others did not. Most participants in frontline positions and with less security found their work physically and emotionally draining, and had less access to workplace accommodations and benefits.

Inequitable access to workplace accommodations and benefits to support health and recovery in specific jobs or occupational groups is likely to worsen existing inequities surrounding long COVID. It is known that the negative effects of acute COVID-19 have been disproportionately experienced by certain social groups (e.g., racialized and low income),<sup>51</sup> and that the lowest income groups have the least access to paid sick days in Canada.<sup>52</sup>

Although knowledge is still developing, some research has shown a higher prevalence of long COVID in lower income groups and some ethnoracial groups (e.g., people from Latinx backgrounds in the US), and higher risk for those unable to rest early after developing COVID-19.<sup>53,54,55</sup> There is also some indication of inequities in accessing limited long COVID health services.<sup>56</sup> With the additional layer that those in better jobs earn higher incomes and have access to short-term and extended sick leave, existing inequities are likely to widen without intervention.

Financial pressures faced by participants were more acute for those who were unable to work and without access to adequate income supports. Other sources have raised the need for better health and social infrastructure as safety nets in response to the ongoing problem of long COVID. These include programs that address the potentially significant financial impact of not being able to work. 57,58 Baseline actions include expanding paid sick leave, improved accommodations for workers, and greater and more timely access to disability benefits.

As with other chronic conditions, a lack of understanding by employers and others has been a challenge for patients in gaining access to disability benefits and leave for those who are unable to work. <sup>59</sup> The defining of long COVID as a disability is a crucial step in enabling access to benefits and accommodations for those who need them. <sup>60</sup> Long COVID has been characterized as a potential "mass-disabling event" by Canada's chief science advisor, <sup>61</sup> which highlights the magnitude of disability it could cause. In this light, governments and employers should take this opportunity to urgently respond to the gaps in existing social infrastructure for people with disabilities in Canada.

For some participants in this study, the stress of coping with long COVID had undermined their mental health. Managing symptoms at work and anxiety around becoming re-infected in the workplace was particularly stressful for those participants working in frontline positions. Other sources have also highlighted the need for responses to long COVID that support emotional and mental well-being. These responses should especially account for the needs of those working in precarious positions without access to benefits or paid sick days. Addressing inequities in access to mental health supports will also be important for equitable responses to long COVID.

#### Limitations

The limitations of this research are mostly due to the sample size and composition, which prevents generalizations across specific sociodemographic characteristics such as ethic/racial identity. This means that conclusions cannot be drawn about which sub-groups had more difficulty at work or worked in more precarious positions. Nevertheless, clear themes emerged around the risks of precarious employment conditions and the importance of economic and other supports for facilitating recovery from long COVID. Similarly, the analysis does not systematically compare experiences at work according to when people became sick with long COVID, and therefore may miss potential differences in work experiences across the different waves or stages of the pandemic (e.g., when income benefits were more widely available). The caregiver sub-sample was very small due to difficulties recruiting this group. Although caregiver participants knew whether their family or friends with long COVID were working, they were generally less aware of the more specific work-related situations (e.g., whether there was a plan for return to work or the details of income support situations). As a result, the data on work from this group was somewhat limited. The experiences of this sub-sample group will be explored in greater depth in a forthcoming Wellesley Institute piece on long COVID and caregiving.

Finally, because this research focused on the broad experiences of people living with long COVID in the GTA, interviews covered a wide range of topics of which work was only one. While work was a clear focus and concern of most participants, there may be gaps in the data due to the wider scope of the investigation. Future research focusing solely on work experiences could expand details on specific employment-related areas such as detailed descriptions of return-towork options and approaches.

#### CONCLUSION

To our knowledge, this research is the first in-depth qualitative study exploring the workrelated experiences of people with long COVID in the GTA. As these findings and other emerging research on long COVID show, many people with prolonged symptoms from COVID-19 face challenges at work. As well, experiences vary considerably with respect to the level of support that workers receive from employers, including access to sick leave and other benefits. Income supports for those who cannot work were also identified as important in this study.

Inequities that already exist with respect to the risk and outcomes around COVID-19 are likely to be magnified if workers in precarious positions continue to lack access to the conditions necessary for protecting health. Workplace conditions that support those with long COVID to continue to work, take sick leave when needed, and return to work in a way that supports rest and recovery should be accessible to all workers. To have these options accessible and without financial penalty or stress is crucial to cultivating a culture where workers' health is prioritized by employers, different levels of government, other decision-makers, and society in general.

The policy implications of the findings presented in this report have been developed in a companion piece. This piece outlines specific actions to be taken to address long COVID workrelated challenges. The general areas of recommended policy action relevant to work are as follows:

- 1. Mobilize knowledge to increase awareness of interested parties (employers, workers, unions, insurance companies, other benefit providers) on long COVID and how it impacts workers.
- 2. Develop implementable workplace plans to support workers with long COVID, including provision of worker-centered accommodations.
- 3. Increase access to paid short- and long-term sick leave for all workers.
- 4. Improve equitable access to workplace benefits that support symptom management and treatment for workers with long COVID, including mental health supports.

#### **APPENDIX**

## Additional information about study design – Inclusion criteria and recruitment strategy

The inclusion criteria were developed in order to fulfil the objective of better understanding the experiences of adults living in the GTA. They were developed with an understanding that many people with long COVID would not necessarily have a formal diagnosis from a healthcare provider. In fact, it was postulated that including any criteria around a COVID-19/long COVID diagnosis would exclude individuals with barriers to access to healthcare services and related socioeconomic resources from study participation. As such, potential participants were asked to self-identify as having ongoing symptoms from a previously acute COVID-19 infection that lasted three months or longer, in line with the WHO definition of post-COVID-19 condition (2021).

Participant recruitment required ongoing dissemination of study information over a six-month period. Study recruitment information was shared using several strategies to reach eligible participants. Information was shared with various community organizations offering health and social services to residents in the GTA. Community agencies were asked to disseminate study materials via email lists, newsletters, and to staff members who might have the opportunity to share materials with potential participants. Individuals interested in participating in the study contacted researchers via email or phone and were screened for their eligibility.

Recruitment efforts were initially targeted to community agencies located in GTA neighbourhoods where the negative impacts of COVID-19 were greatest (e.g., highest rates) during the first year and a half of the pandemic. In April 2021, Ontario's Science Table found that Toronto neighbourhoods with the highest proportion of essential workers in nonhealthcare settings continued to experience a 3-fold higher incidence of COVID-19 infections as compared to neighbourhoods with fewer essential workers. The disproportionate burden of COVID-19 on low income, essential workers, and racialized people has been confirmed by other studies. For these reasons recruitment began in outer suburb areas in Toronto which had been harder hit in an effort to reach participants who had been particularly impacted by COVID-19, who faced greater barriers accessing the healthcare system, and who were from a more diverse sociodemographic background than had generally been represented in qualitative research on long COVID at that time.

This approach was expanded over the course of recruitment to reach a broader number of organizations and participants across the GTA. Study and recruitment information was also posted on social media and shared with administrators of online social media groups of people living with long COVID in Ontario and Canada. Online community group administrators were also asked to share study materials with their members.

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