



NHCC

NEUROLOGICAL HEALTH CHARITIES CANADA

COVID-19 and Brain Conditions: The need to examine an overlooked, urgent issue

Written Submission to the Standing Committee on Health for its Study on COVID-19

Submitted By: Neurological Health Charities Canada

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Summary of Recommendations

NHCC recommends that the Standing Committee on Health carry out a study to focus on the important issue of COVID-19 and brain conditions. We suggest it cover the following areas:

1. Determine what research is currently underway that is examining how COVID-19 impacts the central and peripheral nervous systems and the implications for individuals already impacted by brain conditions and individuals who have developed brain conditions because of COVID-19; and
2. Engage with research experts in basic, clinical and population health research to determine what areas of research should be prioritized to provide answers to the issue of negative impacts of COVID-19 and brain conditions and what is needed to support individuals who are impacted.

Neurological Health Charities Canada (NHCC) is a coalition of organizations that represent people with brain diseases, disorders and injuries in Canada. Brain conditions – brain illnesses, disorders and injuries – are one of the leading causes of disability in Canada and, indeed, worldwide. One in three Canadians (10 million) will have a brain condition in their lifetime. Brain conditions affect people at all stages of the lifespan: children living with cerebral palsy, young adults with brain injuries or spinal cord injuries, women and men in mid-life with dystonia and older individuals with Parkinson’s disease.

People with brain conditions – like all Canadians – have experienced many negative impacts because of the COVID-19 pandemic and the resulting necessary shutdown of much of Canadian society. However, people living with brain conditions, their families and caregivers are also experiencing the additional stress of having to live with chronic diseases and injuries including increased depression and anxiety during the pandemic.

They have experienced cancelled physician and hospital appointments, postponed or cancelled rehabilitation services, shortages of essential medications, suddenly scarce medical supplies such as face masks and catheters. They have faced the additional challenge of not having their usual programs and services provided by the brain health charity on which they have come to rely.

While our member organizations quickly and largely successfully transitioned to delivering online services and telephone support programs, it is impossible to replace face-to-face programs and services. NHCC organizations have done this in the face of declining fundraising revenues and the dire necessity of having to lay off dedicated and experienced staff.

Another important issue, but one that has been little examined or discussed, is the impact COVID-19 is having on two groups of Canadians:

- Individuals who have a brain condition who now live with the fear of developing COVID-19 and the unknown consequences of the virus on their existing brain condition; and
- Individuals who have had COVID-19 and have not recovered. Many of these so-called “long haulers” have neurological and/or psychiatric damage because of the COVID-19 infection.

Therefore, NHCC recommends to the Standing Committee on Health that it carry out a study to focus on this important issue of COVID-19 and brain conditions. We suggest it cover the following areas:

1. Determine what research is currently underway that is examining how COVID-19 impacts the central and peripheral nervous systems and the implications for individuals already impacted by brain conditions and individuals who have developed brain conditions because of COVID-19; and

2. Engage with research experts in basic, clinical and population health research to determine what areas of research should be prioritized to provide answers to the issue of negative impacts of COVID-19 and brain conditions and what is needed to support individuals who are impacted.

Background

It is important that the question of what might happen if a person with a brain condition becomes infected should be thoroughly examined now and proactively in the coming years. NHCC is pleased to see in the spring 2020 CIHR COVID-19 competition there were several research projects approved that are studying aspects of brain health in the context of COVID-19. It is a good but small start.

The Government of Canada itself notes that people with certain conditions such as dementia or having had stroke are at higher risk of having more severe outcomes if infected by COVID-19.ⁱ The Centers for Disease Control and Prevention (USA) lists people with neurological conditions as being possibly at risk for more severe COVID-19 infection outcomes and notes further research is needed.ⁱⁱ

In terms of the “long haulers”, while initial research and treatment relating to COVID-19 focused on the respiratory system, there are an increasing number of reports in scientific journals that the virus is causing neurological and/or psychiatric damage, resulting in symptoms of psychosis or symptoms similar to Parkinson’s disease, dementia, multiple sclerosis and encephalitis. For example, two UK-based studies (one in *Brain*ⁱⁱⁱ and one in *The Lancet*^{iv}) found both neurological and neuropsychiatric complications in people who had experienced COVID-19 infections.

The severity of the neurological/psychiatric involvement was not linked to the severity of the respiratory involvement. While these are small, early studies they do underline the need for researchers and clinicians treating patients to know how extensive neurological/psychiatric involvement might be, how to treat the brain involvement when it occurs and what recovery is in both the short and long term.

A study conducted in New York City and published in the journal *Neurology* detected neurologic disorders in 13.5% of people (one out of seven) with COVID-19 and were associated with increased risk of in-hospital mortality and decreased likelihood of discharge home.^v The most common disorders were toxic/metabolic encephalopathy, stroke, seizure and hypoxic/ischemic brain injury.

Work done by the National Institute for Health Research in Great Britain also underlines the need for much more attention to be paid right now on COVID-19 and brain conditions. In an online article, the National Institute for Health Research Centre for Engagement and Dissemination stated:

“It is increasingly clear that for some people there is a distinct pathway of ongoing effects. There is an urgent need to better understand the symptom journey and the clinical risks that underlie that. People, their families and healthcare professionals need realistic expectations about what to expect., The fluctuating and multisystem symptoms need to be

acknowledged. A common theme is that symptoms arise in one physiological system then abate only for symptoms to arise in a different system...There are significant psychological and social impacts that will have long-term consequences for individuals and for society if not well managed.”^{vi}

Others have recognized the need for more attention to be given to COVID-19 and brain conditions. In a February 8, 2021 opinion article in *The Globe and Mail*, Inez Jabalpurwala, global director of Viral Neuro Exploration, wrote: “Government and research funders should expand investment in COVID-19 research and make the study of viral effects on the brain a priority, beginning with COVID-19 survivors.” She goes on to enumerate five practical and do-able next steps.^{vii} VINEx was created early in the pandemic to draw attention to the brain health impacts of COVID-19, and the need for increased investment in interdisciplinary research, centred on Canadians who have or develop brain conditions.

In conclusion

There is an opportunity for Canada, with its recognized strength in brain research, to contribute to this much needed area of scientific endeavour. The Standing Committee on Health could be the catalyst to bring together experts in research, clinicians, service providers and people with the lived experience to examine what is needed to confront this emerging area. NHCC is willing and able to bring the expertise of Canadians with the lived experience to the table, and we look forward to the opportunity to work together in the near future.

Contact

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References

ⁱ Government of Canada, PHAC. People who are at risk of more severe disease or outcomes from COVID-19. Accessed at: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/people-high-risk-for-severe-illness-covid-19.html>

ⁱⁱ Centers for Disease Control and Prevention. Feb. 22, 2021. People with Certain Medical Conditions. Accessed at: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

ⁱⁱⁱ Paterson, RW et al. The emerging spectrum of COVID-19 neurology: clinical, radiological and laboratory findings, *Brain*, July 8 2020.

^{iv} Varatharaj, A et al. Neurological and neuropsychiatric complications of COVID-19 in 153 patients: a UK-wide surveillance study, *The Lancet*, June 25, 2020.

^v A Prospective Study of Neurologic Disorders in Hospitalized Patients With COVID-19 in New York City. Frontera et al. *Neurology*, Jan 2021.

^{vi} Living with Covid19. Published on 15 October 2020. doi: 10.3310/themedreview_41169. Accessed at: <https://evidence.nihr.ac.uk/themedreview/living-with-covid19/#Key>

^{vii} Jabalpurwala, I, Canada should lead the effort to help COVID long-haulers. Feb. 8, 2021. *The Globe and Mail*. Accessed at: <https://www.theglobeandmail.com/opinion/article-canada-should-lead-the-effort-to-help-covid-long-haulers/>