VIEWPOINT

Addressing the Long-term Effects of COVID-19

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Multimedia

The COVID-19 pandemic is the most significant medical and public health challenge the US has encountered in the last 100 years. As of July 26, 2022, an estimated 90 million cases of COVID-19 have been reported in the US, with an estimated 1 million COVID-19–related deaths. The current number of SARS-CoV-2 infections is difficult to estimate accurately, considering that many individuals with positive self-test results do not seek care or report their infection. At the same time, new coronavirus variants continue to emerge, with Omicron subvariants such as BA.5 and BA.4 now identified as the dominant circulating strains.

From the start of the pandemic, infected individuals exhibited different patterns of recovery. Some patients partnered with other groups of patients with similar or overlapping sets of symptoms and voiced their concerns to health care professionals, allowing recognition of what has been referred to as "Long COVID."[1]

In defining Long COVID, 2 perspectives need to be balanced: the need to learn more and avoid premature definitions that inappropriately exclude patients in need of care, and the need to establish interim definitions to enable access to health care and disability services as the science of Long COVID continues to emerge.

Long COVID Terminology

As a lay term, "Long COVID" refers to a varied set of conditions, possibly with related underlying pathophysiological causes, that likely will affect the health of many people in the US and worldwide for years to come. Two technical terms have emerged. The first, "post–COVID-19 conditions" (PCC), is a broad term that captures illness due to both the direct and indirect effects of the virus. At this point, it is equivalent to Long COVID.[2] For example, the term PCC is useful in various clinical settings, assessing the burden to the health care system, and surveillance.

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The second, "postacute sequelae of SARS-CoV-2 infection" (PASC), aims to capture the direct effects of the virus.[3] PASC is used often in clinical contexts and is critical to the medical research community aiming to understand the root causes of Long COVID. Without an evidence-based diagnostic test, other illnesses need to be excluded in reaching a diagnosis of Long COVID. Importantly, since October 2021, the Centers for Disease Control and Prevention (CDC) established an *ICD-10* code (code U09.9, post COVID-19 condition, unspecified) for classifying diagnoses and reasons for visits in all health care settings. The *ICD-10-CM* code for Long COVID is gaining acceptance and provides a method to assess and possibly validate Long COVID definitions.[3] However, to address the challenges ahead, it will be important to characterize and categorize the more than 200 symptoms and signs and 50 conditions that "define" Long COVID.[2]

Presidential Memorandum on Long-term Effects of COVID-19

On April 5, 2022, the White House issued a presidential Memorandum on Addressing the Long-Term Effects of COVID-19.[4] This memo directs the federal government to provide care for 3 large groups of affected persons: those with Long COVID and associated conditions; those experiencing behavioral health challenges related to COVID-19; and those grieving the loss of loved ones, friends, and neighbors.

Persons With Long COVID and Associated Conditions

The first group includes individuals with Long COVID and associated conditions. Long COVID already has affected a substantial number of people, and this number may continue to increase as new COVID-19 cases occur. Recent studies demonstrate the potential enormity of the problem for the US health care and public health systems. Long COVID can affect nearly every organ system and can manifest as new-onset chronic disease such as heart disease, diabetes, kidney disease, hematologic disorders, neurologic conditions, and mental health disorders.[2]

A 2022 study by the CDC that analyzed electronic health records and included 63.4 million individuals estimated that 1 in 5 adult COVID-19 survivors aged 18 to 64 years and 1 in 4 survivors aged 65 years and older have a health condition related to their previous COVID-19 illness.[5] A parallel modeling study estimated that 4.3 million to 9.7 million US adults have new long-term symptoms that limit their daily activities after SARS-CoV-2 infection and that women may be disproportionally affected.[6] Furthermore, based on self-reported data from 62 000 adults who participated in the Census Bureau's online Household Pulse Survey in June 2022, 35.1% of those who reported having had COVID-19 (n = 25 049) reported experiencing Long COVID symptoms at some point and 18.9% reported having Long COVID symptoms currently.[7] While estimates of incidence and prevalence of Long COVID vary across studies and settings, the breadth of symptoms and conditions that are manifestations of Long COVID and the potential cumulative health effects are consistent throughout the scientific literature.

Persons With Behavioral Health Conditions

The second group included in the presidential memo are those with behavioral health conditions related to

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COVID-19. During the pandemic, there has been an increase in mental health and substance use disorders, and this surge has added to the mental health crisis that was extant before the pandemic. Fear, anxiety, anger, and depression have been common emotions as individuals coped with the stressors associated with the COVID-19 pandemic.

In the Census Bureau's online Household Pulse Survey from May 2020 onward (samples vary from n = 39 400 to 118 800), the percentage of US adults who reported feelings of anxiety and depression had peaks of 41% (July 2020) and 42.6% (November 2020) and remained substantial through last month, 33% in June 2022; this rate was more than 4 times higher than in 2019.[7,8] Increases in stress-related symptoms and mental health diagnoses (such as anxiety, depression, insomnia, and obsessive-compulsive disorders) have been reported as a consequence of COVID-19 and the pandemic.[2] Drug overdose deaths, which were already increasing before 2020, increased rapidly during the COVID-19 pandemic, with a record 107 000 deaths in 2021.[9]

Persons Who Experienced Personal Loss

The third group included in the presidential memo are those who experienced COVID-19–related loss of loved ones, family members, or neighbors. According to a report from Imperial College London, more than 200 000 US children have lost at least 1 parent to COVID-19.[10] Another study estimated that every US COVID-19 death left behind approximately 9 bereaved kin. Persons of certain racial and ethnic groups have been disproportionately affected. Providing support and resources to individuals who have lost loved ones during the pandemic remains an important priority in the process of grief and bereavement.

Government Response

The presidential memo calls for a whole-of-government response starting with the publication of 2 reports, which were released August 3, 2022: *Services and Supports for Longer-Term Impacts of COVID-19 Report* and the *National Research Action Plan on Long COVID*.[4] The first report outlines federally funded supports and services for individuals who have experienced disabilities due to Long COVID and associated conditions. In addition, the report lists federally funded supports and services for individuals experiencing the effects of COVID-19 in the areas of mental health, substance use, and bereavement.

The research plan builds on the research approach already begun across the federal government to improve current understanding of the underlying biological causes, epidemiology, and effects of Long COVID; foster development of new diagnostics and treatments; inform decisions related to support services and interventions; develop, implement, and scale innovative models of care delivery; improve data sharing and transparency among researchers; and explore the influence of Long COVID on persons who are underserved by the health care system and public health infrastructure.

Conclusions

Long COVID and associated conditions as well as the longer-term sequelae of the pandemic will continue to affect patients and families. The medical and public health community have made dedicated efforts during the last 2½ years to stopping the spread of this deadly coronavirus and have implemented prevention methods, developed treatments, and released vaccines that have been central to reducing initial COVID-19 infections and preventing Long COVID.

It is important to focus a new lens on the pandemic and direct much-needed attention to Long COVID. Taking care of affected patients presents challenges given the incompleteness of research, the lack of sufficient diagnostics support, and pervasive problems with access to services. The provisions in the presidential memo are important elements for mounting an effective approach for addressing the long-term effects of COVID.

ARTICLE INFORMATION

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