

Many Americans with long COVID have trouble accessing care, reports study

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Getting care in the United States for lingering COVID-19 symptoms can

be challenging, affecting long-term health and ability to work, a new study finds.

Adults with so-called long COVID have had greater challenges with [health care access](#) and affordability than other adults, and these barriers to care have implications for their well-being, said lead researcher Michael Karpman, a research associate in the Urban Institute Health Policy Center in Washington, D.C.

"Further efforts are needed to develop long COVID treatments, provide guidance to clinicians, and set standards for defining medically necessary care and other insurer practices in order to reduce delays in access to tests and treatments," he said.

Part of the problem is that no standard diagnostic tests and treatments for long COVID exist, Karpman said.

"Providers may not have enough information about how to address a patient's concerns. This could lead them to conduct unnecessary tests or make inappropriate referrals. Without clear standards for care, insurers may deny payments for some services," he said.

Long COVID was defined by the research team as having symptoms beyond four weeks.

Karpman and his colleagues collected data on nearly 9,500 U.S. men and women ages 18 to 64 who took part in an internet-based survey, conducted from June 17 to July 5, 2022.

Thirty-six percent said they had been diagnosed with COVID-19 and 22.5% said they suffered from long COVID.

The researchers found that those with long COVID were less likely to

get the [health care](#) they needed than those who had had COVID, but not long COVID, or those who had never had the virus.

Nearly 3 in 10 (27%) said cost kept them from getting needed care. Finding a doctor taking on new patients was a problem for 16% of long COVID sufferers, while 22% said they couldn't get a timely appointment. Insurance obstacles prevented nearly 17% from getting care or [prescription medications](#), Karpman's team found.

There are differences in the demographics of adults with long COVID but after controlling for these differences, all patients with long COVID are still more likely to have access challenges, Karpman said.

Staci Lofton, senior director for health equity at Families U.S., which advocates for access to health care, said the burden of long COVID strikes the poor and minorities hardest. It has become very hard for people to get Supplemental Security Income (SSI) from Social Security for long COVID, she said.

"There's an increasing number of people who are applying for SSI due to long COVID, but depending on their state requirements, may not qualify for Medicaid or just don't have social resources support to navigate the process," said Lofton, who was not involved with the study.

The system works to discourage individuals from applying, she said.

"We aren't even prepared to address long COVID as a disability and the stigma that comes with it, given the populations most burdened by COVID. Also, Black and brown communities, the very communities most likely to need long COVID care, are more likely to be in an area where the demand for care is not well met," Lofton said.

Karpman said that to cope with these problems, it's necessary to speed

up research on long COVID, launch clinical trials of potential treatments and develop clinical guidelines. Collecting data on claim denials for long COVID-related care will help paint a clearer picture, he said.

Arielle Kane, director of Medicaid initiatives at Families U.S., cited another problem for folks with lingering COVID: "People with long COVID are more likely to be working fewer hours after their infection than those who didn't have long COVID. This affects both their [cash flow](#) but also their health insurance status—those who work less are more likely to be uninsured."

Kane, who was not part of the study, said standards of care need to be developed as more clinical data become available.

"Meanwhile," she said, "people with complex illnesses often need help navigating their coverage, finding in-network providers and appealing denials of care. This sort of consumer assistance should be more widely available, and should reach people who speak Spanish, English and other languages. People also need better access to long COVID clinics.

"This problem isn't going anywhere," Kane added. "So it may be time to figure out how to integrate long COVID into medical school curriculum."

The report was published online April 10 in the journal *JAMA Network Open*.

More information: See the [U.S. Centers for Disease Control and Prevention](#) for more on long COVID.

Michael Karpman et al, Health Care Access and Affordability Among US Adults Aged 18 to 64 Years With Self-reported Post-COVID-19 Condition, *JAMA Network Open* (2023). [DOI:](#)

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