EPAPER   METRO   WEATHER   POLITICS   SPORTS   BUSINESS   WATCH: GLOBE TODAY   PUZZLES   SIGN IN →

Long COVID may be far more common than previously known

A new study from researchers at Mass General Brigham suggests racial disparities and the difficulty in diagnosing the condition may be leading to a massive undercount.

By Adam Piore Globe Staff, Updated November 16, 2024, 4:45 p.m.

Part of the algorithm that can diagnose long COVID by scanning medical records can be seen behind Shawn Murphy (left), chief research information officer at Mass General Brigham and co-director of its Center for AI and Biomedical Informatics, and Hossein Estiri, head of AI Research at CAIBILS, co-authors the algorithm. DANIELLE PARHIZKARAN/GLOBE STAFF

Almost one in four Americans may be suffering from long COVID, a rate more than three times higher than the most common number cited by federal officials, a team led by Boston area researchers suggests in a new scientific paper.

The peer-reviewed study, led by scientists and clinicians from Mass General Brigham, drew immediate skepticism from some long COVID researchers, who suggested their numbers were "unrealistically high." But the study authors noted that the condition is notoriously difficult to diagnose and official counts also likely exclude populations who were hit hardest by the pandemic but face barriers in accessing healthcare.

"Long COVID is destined to be underrepresented, and patients are overlooked because it sits exactly under the health system's blind spot," said Hossein Estiri, head of AI Research at the Center for AI and Biomedical Informatics at Mass General Brigham and the paper's senior author.

BOSTON GLOBE TODAY

Gronk on Maye, Mayo, a   SHARE

5:44

WATCH: What does the Super Bowl champion think of the rookie QB and his former teammate? Plus, why he's not convinced Belichick will return to coaching.

NOW PLAYING

Gronk on Maye, Mayo, and Belichick   **Juan Soto's chances of landing in Boston**   **Are the Pats on the cusp of back-to-back wins?**

MOST POPULAR ON BOSTONGLOBE.COM

1. Tensions over abortion erupt as protesters confront Men's March in Boston
2. History tells us there are very few sluggers like Juan Soto, the top MLB free agent this offseason
3. When the University of Florida's president resigned, was it all about academic rankings?
4. Trump names fossil fuel executive Chris Wright as energy secretary
5. Ken Burns on why no one, not even Elon Musk, can compare with Leonardo da Vinci
6. Long COVID may be far more common than previously known
7. Led by Derrick Henry and Saquon Barkley, older running backs are enjoying a resurgence in NFL

VIEWS FROM OUR COLUMNISTS

YVONNE ABRAHAM
Giving carte blanche to abusers

JENEÉ OSTERHELDT
Donald Trump won the presidency. Freedom is still ours to fight for.

Though the pandemic hit hardest in communities of color where residents had high rates of preexisting conditions and many held service industry jobs that placed them at high risk of contracting the virus, the vast majority of those diagnosed with long COVID are white, non-Hispanic females who live in affluent communities and have greater access to healthcare, he said.

Moreover, many of the patients who receive a long COVID diagnosis concluded on their own that they have the condition and then persuaded their doctors to look into it, he said. As a result, the available statistics we have both underestimate the true number of patients suffering from the condition and skew it to a specific demographic.

"Not all people even know that their condition might be caused or exacerbated by COVID," Estiri said. "So those who go and get a diagnosis represent a small proportion of the population."

Diagnosis is complicated by the fact that long COVID can cause hundreds of different symptoms, many of which are difficult to describe or are easily dismissed, such as sleep problems, headaches or generalized pain, Estiri said. According to its formal definition, long COVID occurs after a COVID-19 infection, lasts for at least three months, affects one or more organ systems, and includes a broad range of symptoms such as crushing fatigue, pain, and a racing heart rate.

The US Centers for Disease Control and Prevention suggested that in 2022 roughly 6.9 percent of Americans had long COVID. But the algorithm developed by Estiri's team estimated that 22.8 percent of those who'd tested positive for COVID-19 met the diagnostic criteria for long COVID in the 12 months that followed, even though the vast majority had not received an official diagnosis.

(from left) Shawn Murphy, chief research information officer, Hossein Estiri, head of AI Research, Jiangh Cheng, research scientist, and Jiazi Tian, data scientist, hold a meeting at Mass General Brigham. Estiri, Murphy, Tian and Cheng were authors on the algorithm that can diagnose long COVID by scanning medical records. All work has been done through the Center for AI and Biomedical Informatics of the Learning Healthcare Systems (CAIBILS). DANIELLE PARHIZKARAN/GLOBE STAFF

To calculate their number, Estiri's team built a custom artificial intelligence tool to analyze data from the electronic health records of more than 295,000 patients served at four hospitals and 20 community health centers in Massachusetts. The AI program

pulled out 85,000 people who had been diagnosed with COVID through June 2022, and then applied a pattern recognition algorithm to identify those that matched the criteria for long COVID in the 12 months that followed.

Some researchers questioned the paper's conclusions. Dr. Eric Topol, author of the 2019 book "Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again," said the medical field is still divided over precisely what constitutes long COVID, and that complicates efforts to program an accurate AI algorithm.

"Since we have difficulties with defining long Covid, using AI on electronic health records may not be a way to make the diagnosis accurately," said Topol, who is executive vice president of Scripps Research in San Diego. "I'm uncertain about this report."

Dr. Ziyad Al-Aly, chief of research and development at the VA St. Louis Health Care System, and an expert on long COVID, called the 22.8 percent figure unrealistically high and said the paper "grossly inflates" its prevalence.

"Their approach does not account for the fact that things happen without COVID (not everything that happens after COVID is attributable to COVID)— resulting in significant over-inflation of prevalence estimate," he wrote via email.

Estiri said the research team took several measures to validate its AI algorithm, retroactively applying it to the charts of 800 people who had received a confirmed long COVID diagnosis from their doctor to see if it could predict the condition. The algorithm accurately diagnosed them more than three quarters of the time.

The algorithm scanned the records for patients who had a COVID diagnosis prior to July 2022, then looked for a constellation of symptoms that could not be explained by other conditions and lasted longer than two months. To refine the program, they conferred with clinicians and assigned different weights to different symptoms and conditions based on how often they are associated with long COVID, which made them more likely to be identified as potential sufferers.

Now that the initial paper has been published, the team is building a new algorithm that can be trained to detect the presence of long COVID in the medical records of patients without a confirmed COVID-19 diagnosis so the condition can be confirmed by clinicians and they can get the care they need, Estiri said.

But the most exciting part of the new research, Estiri said, is its potential to facilitate follow-up research and help refine and individualize treatment plans. In the months ahead, Estiri and his co-principal investigator Shawn Murphy, chief research information officer at Mass General Brigham, plan to ask a wide variety of questions by querying the medical records in their sample. Does vaccination make a patient more or less likely to develop the condition? How about treatment with Paxlovid? Do the symptoms patients develop differ based on those factors? What are the genomic characteristics of patients who are suffering from cardiovascular symptoms as opposed to those whose symptoms are associated with lung function or those who

crash after exercising? Can they identify biomarkers in the bloodstream that could be used for diagnosis?

They have already prepared studies on vaccine efficacy, the effect of age as a risk factor, and whether the risk of long COVID increases with the fourth and fifth infection, Estiri said.

"We were waiting for this paper to come out," he said. "So now we can actually go ahead with the follow-up studies. With this cohort we can do things that no other study has been able to do, and I'm hoping it can really help people."

Adam Piore can be reached at adam.piore@globe.com.

MORE ON GLOBE.COM

Tensions over abortion erupt as protesters confront Men's March in Boston
Hundreds of anti-abortion marchers faced off against counter-protesters in Boston as the two sides shouted slogans at each other. Police gave everyone a notice to disperse.

SUNDAY BASEBALL NOTES

History tells us there are very few sluggers like Juan Soto, the top MLB free agent this offseason
Through his age-25 season, Soto, who met with the Red Sox recently, has performed at levels that surpass those of most Hall of Famers.

Ken Burns on why no one, not even Elon Musk, can compare with Leonardo da Vinci
The decorated filmmaker, along with co-directors Sarah Burns and David McMahon, open up about their new film "Leonardo da Vinci."

When the University of Florida's president resigned, was it all about academic rankings?
The University of Florida puts an intense focus on academic rankings, such as those by US News & World Report. So when the university's rankings dropped, new president Ben Sasse was under pressure.

Trump names fossil fuel executive Chris Wright as energy secretary
President-elect Donald Trump has selected Chris Wright, a campaign donor and fossil fuel executive, to serve as energy secretary in a second Trump administration.

Long COVID may be far more common than previously known
A new study from researchers at Mass General Brigham suggests racial disparities and the difficulty in diagnosing the condition may be leading to a massive undercount.

SPORTS MEDIA

There's still no clarity at WZLX after end of Rich Shertenlieb's show, and other sports media notes
WZLX has been airing music in the morning, with Kenny Young — who had been the program director for Shertenlieb's show — occasionally chiming in as the de facto host.

SUNDAY FOOTBALL NOTES

Led by Derrick Henry and Saquon Barkley, older running backs are enjoying a resurgence in NFL
The best free agent acquisitions this year have been veteran, supposedly-past-their-prime running backs. Their

GLOBE MAGAZINE

A woman with cancer needed a miracle from a stranger. A veteran in pain needed one, too.
One donor was a perfect match for Betsy Ehrenberg. But would that person help a complete stranger?

signings were modest, but their impacts
have been significant.

MOST READ IN THIS SECTION

Tensions over abortion erupt as protesters confront Men's March in Boston

Long COVID may be far more common than previously known

ADRIAN WALKER

SJC decides men who patronize high-priced brothels should be treated like any other defendants

See photos and video from the anti-abortion rally in Boston on Saturday

Trailblazing Gloucester woman honored for keeping lighthouses ablaze during 1864 storm

UMass Amherst, MIT issue advice for foreign students, faculty under Trump administration

MOUNTAIN ESCAPES

We spent 12 days on the greatest hiking trail in the world. You can, too.

Red Line trains to be suspended between Harvard and Broadway starting Sunday

THE GREAT DIVIDE

'I want to scream, but I can't.' The hidden world of special education settlements in Mass.

FOLLOW US