

## Article

# Implications of Long COVID for Society: Insights into the Physical, Social, and Financial Impacts from Patient Interviews

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**Abstract:** Long COVID affects millions of people worldwide and has emerged as a major health consequence of the COVID-19 pandemic. While quantitative studies have helped paint a picture of ongoing symptomatology, there are very few longitudinal qualitative studies that present patients' perspectives about the significant and persistent impact Long COVID has on their daily lives. To address this gap, we conducted semi-structured qualitative interviews with nine Long COVID patients about 15 months after we performed an initial set of interviews with those patients who were seeking care at a Long COVID specialty clinic. Most patients that we re-interviewed reported having lingering symptoms that continue to impact their lives. Many described suffering with mental health issues, particularly depression and anxiety. Others described financial stress. Most reported not yet being unable to return to their pre-COVID level of health and well-being. Our work demonstrates the ongoing need to study Long COVID and provide robust social support, mental health resources, and healthcare focused on symptom relief.

**Keywords:** COVID-19; Long COVID; post-acute sequelae of SARS-CoV-2 infection; COVID-19 syndrome; qualitative research



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## 1. Introduction

One of the many unresolved issues from the COVID-19 pandemic is the condition known as Long COVID. The National Academies of Sciences, Engineering, and Medicine (NASEM) recently defined Long COVID as a sequela of COVID-19 infection that persists for at least three months and affects at least one organ system [1]. The symptoms of Long COVID are innumerable and can range from mild to severe. Moreover, the clinical course is highly variable, and the pathophysiology remains under investigation. To date, there are few evidence-based treatments that have emerged for this condition [2].

Given that Long COVID is estimated to affect approximately 7% of adults in the United States (U.S.) [3] and scores of millions of individuals worldwide, it is imperative that we develop a deeper understanding of the long-term consequences of this chronic condition on peoples' lives. Numerous investigators have used scales, surveys, and clinical assessments to quantitatively demonstrate that people with Long COVID have ongoing physical deficits, decreased health-related quality of life, and more mental health issues relative to their pre-COVID state [4–6]. Qualitative studies can augment our awareness and help us more fully appreciate the lived experiences of this population.

We and others have reported qualitative insights about the significant impacts of Long COVID on overall health and well-being, the ability to maintain employment, mental health, and access to care [7–11]. However, most qualitative studies to date have examined how people are doing at a single point in time, creating a paucity of insights into the longitudinal aspects of living with Long COVID. We aimed to close this gap by re-interviewing Long

COVID patients from our original study one year later to learn about their experiences and their unique perspectives.

## 2. Materials and Methods

### 2.1. Study Design and Setting

We conducted a qualitative study comprised of second interviews with Long COVID patients who received care at a post-COVID recovery clinic. The original study has been previously described [11,12]. Briefly, Long COVID patients were interviewed first in August–September 2022 and again in December 2023, approximately 15 months later. The second set of interviews aimed to understand their perspectives about the impact of Long COVID-19 over time.

### 2.2. Study Participants, Data Collection, and Interview Procedures

In the original study, Long COVID patients were recruited to participate in interviews with the help of care team members at a post-COVID recovery clinic. For the first round of interviews, purposeful sampling was used, where eligible participants were 18 years of age or older, were English speakers, self-reported doing well in daily life before contracting COVID-19, and self-reported that Long COVID was having a significant impact on their life at  $\geq 3$  months following acute COVID-19 infection [11,12]. Approximately a year later, all 21 patients who participated in the first round of interviews received an email inviting them to participate in a follow-up interview. Interested patients contacted the study team and were scheduled for follow-up interviews.

Nine people (43%) agreed to participate in the follow-up interviews, while the others did not respond to the invitation. Participants were 43–69 years old (average: 66) and primarily female (56%). Most participants had received at least a first COVID-19 vaccination (67%). Participants were anonymized and labeled LC101 to LC109. Participant characteristics are shown in Table 1.

**Table 1.** Participant characteristics (N = 9).

ID	Age (Years)	Gender	COVID-19 Vaccine Status
LC101	40–49	Female	+
LC102	60–69	Female	+
LC103	40–49	Male	+
LC104	50–59	Female	–
LC105	50–59	Male	–
LC106	50–59	Male	+
LC107	60–69	Female	+
LC108	50–59	Male	+
LC109	60–69	Female	–

Follow-up interviews with Long COVID patients took place approximately 15 months after the initial interview and lasted approximately 55 minutes (range: 35–80 minutes). Study team members conducted interviews with participants by phone using a semi-structured guide. Interview topics included Long COVID symptoms, seeking healthcare, COVID-19 vaccine status, what it is like to live with this condition, including financial and mental health impacts, as well as suggested advice to Long COVID patients and providers. Table 2 provides an overview of the semi-structured interview.

**Table 2.** Overview of the semi-structured interview.

Topic	Example Question
Long COVID symptoms	What Long COVID symptoms are you experiencing at this time? How have your symptoms changed over the past year?
Healthcare	What treatments for your Long COVID have you received in the past year, and how has that gone? Are you still visiting the Post-COVID Recovery Clinic?
Public health measures	As the restrictions around public health measures (such as mask-wearing and social distancing) have changed over time, have you changed your behaviors in any way due to your Long COVID?
COVID-19 vaccination	Have you received a COVID-19 vaccine or booster in the past year? What influenced your decision about vaccination?
Financial impact	Describe the financial impact that Long COVID has had on you and your family this past year. Has your income situation changed this past year due to your experience with Long COVID?
Impact on mental health	How has your experience with Long COVID impacted your mental health over this past year? Have you participated in any support groups for Long COVID?
Advice for others	What advice would you give to someone who has recently developed symptoms of Long COVID? What messages do you have for doctors to improve care for Long COVID patients?

All interviewees provided verbal informed consent to participate in the study and received an electronic \$25 gift card in appreciation of their time. Interviews were audio-recorded, transcribed verbatim, and de-identified. The Ohio State University’s Institutional Review Board approved this work (study ID: 2020B0288).

### 2.3. Data Analysis

Interview transcripts were coded and analyzed using deductive dominant thematic analysis [13], allowing for the categorization of data based on general themes derived from the interview guide, as well as the identification of emergent themes. This approach allowed for a comparison of themes across interviews and enabled us to characterize the impact of the Long COVID on patients over time. We utilized ATLAS.ti version 24 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) qualitative data analysis software to support our coding and analysis process. Considering that Long COVID patients reported many symptoms with significant impact in their first interviews, we were interested in perspectives about how their experience with Long COVID has changed over time, as we report below. The results of the analysis are presented in accordance with the standards for reporting qualitative research (SRQR) [14].

## 3. Results

### 3.1. Long COVID Symptoms

All participants reported symptoms included in the NASEM definition of Long COVID [1] in at least one of their interviews. Responses varied across patients when asked to make comparisons of their symptoms over time, with most patients reporting an improvement of symptoms in their follow-up interview. One participant reported lingering symptoms by explaining, *“I would still say a little bit of brain fog. That has been incredibly persistent and it’s much improved now, but it really has been a three-year battle. I still am post-exertional malaise, you know, I had a pretty busy week a couple weeks ago, and then just absolutely crashed and found it difficult to do anything for a few days.”* Similarly, another participant expressed ongoing issues by sharing, *“I haven’t gotten back to pre-COVID. I still struggle, right now pain is a big one. Pain and I still have the, like the brain fog at times. If I’m too overstimulated, then word finding becomes challenging. Sleep, still. I’m struggling with sleep. I haven’t slept through the night in 30 months.”* Another participant reported feeling much better by sharing, *“I don’t have any [now]. I had had shortness of breath; I just couldn’t get a deep breath. I remember driving home, and not being able to get my breath and not, I couldn’t wait to get out of the car, so I could stand up, so that I could hopefully get a deeper breath because when you sit, you’re scrunched. I feel*

*much better now though.*" A summary of symptoms reported by participants in their first and follow-up interviews is depicted in Table 3.

**Table 3.** Symptoms reported by Long COVID patients over time.

ID	Long COVID Symptoms (Over Time)	Long COVID Symptoms 1st Interview	Long COVID Symptoms Follow-Up Interview
LC101	Same	Persistent fatigue; difficulty concentrating; memory changes	Persistent fatigue; difficulty concentrating; memory changes
LC102	Improved	Shortness of breath; cough	None
LC103	Improved	Persistent fatigue; shortness of breath; cough	Shortness of breath
LC104	Improved	Cough; persistent fatigue; difficulty concentrating; memory changes; recurring headache; lightheadedness; fast heart rate; sleep disturbance; problems with taste or smell; bloating, constipation, and diarrhea	Cough; persistent fatigue; difficulty concentrating; memory changes; sleep disturbance
LC105	Improved with some persistent symptoms	Shortness of breath; cough; persistent fatigue; difficulty concentrating; memory changes; recurring headache; sleep disturbance; bloating, constipation, and diarrhea	Shortness of breath; memory changes; fast heart rate
LC106	Improved with some persistent symptoms	Persistent fatigue; difficulty concentrating; memory changes; lightheadedness; problems with taste or smell; bloating, constipation, and diarrhea	Persistent fatigue; difficulty concentrating
LC107	Improved with some persistent symptoms	Shortness of breath; cough; persistent fatigue; difficulty concentrating; memory changes; problems with taste or smell; bloating, constipation, and diarrhea	Persistent fatigue; difficulty concentrating; memory changes
LC108	Worsened	Shortness of breath; persistent fatigue; difficulty concentrating; memory changes	Cough; difficulty concentrating; memory changes
LC109	Improved with some persistent symptoms	Shortness of breath; persistent fatigue; difficulty concentrating; memory changes	Memory changes, problems with taste or smell

### 3.2. Impacts of Long COVID and Advice to Patients and Providers

When reflecting on their journey with Long COVID, each participant shared a unique experience in terms of symptoms and impact on their overall health and well-being. Most participants also shared advice for people experiencing Long COVID and for their providers. These topics are discussed in below, with representative quotes from the participant follow-up interviews, and a full summary is provided in Table 4.

Most participants mentioned that their experience with Long COVID had resulted in a significant financial impact for them and their family. For example, one participant whose symptoms had worsened over time shared, *"Point-blank I lost a job over this. And that is to myself, is to, concerns for employment, anxiety about that, you know, what happens if I lose another role. The standard of living that we've had for all these years is diminished because in the newest role I had, I had to take a pay cut. So, there has been quite a bit of struggle there."* In contrast, a participant who was no longer experiencing any Long COVID symptoms shared, *"No [financial impact], because I had plenty of sick time. I was off maybe three weeks. So no, there, and I went back to work then. I just worked through it."*

In addition, many participants noted their mental health had been impacted by their experience with Long COVID. One participant felt that their mental health had not improved over the past year. They shared, *"It kind of just has stayed the same. I still get very emotional about it. I have you know, I mean, I'm sitting here holding back tears talking to you now because I could really fall apart. So, and it's always been that way, it hasn't gotten worse, it hasn't gotten better. I don't know if it ever will."* Another participant similarly expressed a negative

impact on their mental health, “It’s a strain, and I don’t know if it’s so much a strain as between the physical part of not being able to do what you do or used to do, or the financial strain on the health end of it. I mean, I can’t tell you which one it is. I mean there’s days that, you know, you feel down. I mean it’s just; you get one of those, is when’s this going to change?”

**Table 4.** Patient reflections on their Long COVID experience one year later.

Patient & Topic	Financial Impact	Mental Health Impact	Advice to Patients	Advice to Providers
LC101 *	Significant. Working less. Paused schooling. Finances are tight.	Significant. Stress around marriage and finances.	None provided.	None provided.
LC102	None overall, but no longer taking on over-time work.	Improved. Anxiety has gone away.	Keep going. Don’t dwell on it.	None provided.
LC103 *	Initial impact, but better now.	Significant. Anxiety about getting sick.	Keep spirits up.	None provided.
LC104 *	More medical bill copays but making it work.	Significant. Anxiety about getting sick.	Try to immediately get in long COVID clinic. Don’t do it alone.	Listen to patients.
LC105 *	Significant. Less income and numerous medical bills.	Significant. Struggle with rejection. Thankful to be alive.	Get into therapy.	Realize there is a lot unknown.
LC106 *	Significant. Working less. Dealing with high costs for medical bills.	Significant. Difficulty with mental and physical impacts.	Buckle seatbelt and hold on.	Realize each patient is different. Easier appointments.
LC107 *	Significant. Unable to work. Friends helping.	Significant. Ongoing depression and feelings of helplessness.	Acknowledge it is real and happening. Don’t be in denial.	Be kind and believe patients.
LC108	Significant. Lost job. New job with lower pay.	Significant. Anxiety. Afraid will lose a job.	Seek out books about long COVID.	Acknowledge that this Long COVID needs to be addressed.
LC109 *	Significant. Working less. Loss in income due to “forced” early retirement.	Improved. Depressed and anxiety improvements with counseling.	Accept it. Stay positive. Take advice from others.	Realize each patient is different.

\* Several participants reported having health issues in addition to any symptoms they may have experienced with Long COVID, making it difficult to distinguish the impact of those health issues on their overall wellbeing.

Several participants offered words of support to other Long COVID patients and emphasized the need to stay positive throughout their journey with this condition. For example, one participant shared, “Accept it. Take any advice, any suggestions, any help that you can get. Stay positive that, you know, maybe it’s going to work, maybe it’s not. But let’s think that it will and if it doesn’t let that be okay, that that maybe that procedure, that exercise, or that whatever, therapy, whatever, that did not help but maybe the next one will. Stay positive because if you sit and wallow in self-pity, you’re never going to get better.” Another participant similarly shared, “Keep going. Get out as much as you can and do everything you can, don’t sit around and dwell on it. Like I got out and rode the bike or get out and walk or go shopping. . .” The need to get medical help was the focus of another participant who explained, “Try to immediately get into a Long COVID clinic. Don’t try to do this on your own, you know, get in with good doctors and make sure that they hear what you’re saying. I would tell them; they’re not going crazy because you feel like it at times because these symptoms can be so bizarre.”

A few participants were also willing to offer advice for providers treating patients with Long COVID. One participant felt it would have been helpful for their provider to further investigate their symptoms and treatment options despite not much being known about this condition. They shared, “I would say, make sure that the patient knows that you hear them. Instead of saying, huh? I don’t know if that’s Long COVID or not. You know, trying to figure

*out, and it's okay to say, there's not enough research out, we are learning, but I'm not giving up on you."* Another participant similarly shared, *"Just because we look all right doesn't mean we are. And that's the, I think that that's probably true, you know both physically and mentally."*

#### 4. Discussion

Our study of patients with Long COVID showed that even though symptoms may have improved for some people over the past year, most participants continue to suffer with financial, well-being, and mental health deficits compared to their pre-COVID status. These findings align with other research that has documented the disruptive persistence of Long COVID in peoples' lives. Kim et al. conducted a prospective cohort study and followed patients for up to two years after being diagnosed with COVID-19 [15]. Patients in this cohort showed some improvements in quality of life and mental health over time, but many still had persistent symptoms in these areas even after 24 months. Similarly, Mercier et al. assessed patients longitudinally over two years and demonstrated that many patients with Long COVID continued to have anxiety, depression, and worse quality of life compared with a group of patients who had fully recovered from COVID-19 [5]. Tarazona et al. showed significantly lower health-related quality of life in Long COVID patients one year after their initial infection, with the most troublesome problems being pain/discomfort and difficulty accomplishing daily activities [16].

Consistent with other work that shows a variable clinical course, many of our participants showed some improvement over time, and some even described the resolution of symptoms, but others were reportedly doing worse than they had been in our original interviews. Using longitudinal cohort data, Ballouz et al. described the status of Long COVID patients after two years [17] and noted that while most patients reported some symptom improvement or recovery, a small percentage had worsened over time. Overall, 18% of these patients still had symptoms of Long COVID after two years. Data from the RECOVER study showed that 10% of participants still had symptoms at 6 months [18]. More research is needed to fully understand the natural course of Long COVID, including what factors can modify or shorten the recovery time.

Long COVID has had a major impact on the global economy. In the U.S. alone, it is estimated that the cost of reduced quality of life is \$2.2 trillion, lost earnings is \$1 trillion, and increased spending on medical care is \$528 billion [19]. Experts from the European Union estimated a reduction in the labor supply of over 1,000,000 people in 2022 and warned of continued disruption due to increasing use of sick leave, reduced work hours, disability, and chronically diminished overall health [20]. They also noted that these disruptions are disproportionately higher in the service industries such as healthcare and long-term care, which are staffed predominantly by females since Long COVID is more prevalent in females than males [20]. Al-Aly, et al. projected that by 2023, there would be a cumulative global incidence of Long COVID of over 400 million people, resulting in a conservative economic impact of 1% of the global economy [21].

Behind these staggering figures are real people facing significant reductions in their well-being and their ability to be productive citizens. We and others have reported on the detrimental effects of Long COVID on the ability to work, the impact of mental health, and general difficulty returning to pre-COVID status [22–25]. Importantly, Al-Aly, et al. postulate that the increase in chronic diseases as sequelae to COVID infection will overburden our health systems, decrease access to care, and further diminish quality of life [21]. Further, Long COVID has impacted the environment and sustainability efforts. Rana et al. discussed several areas of concern, including climate change, sustainability, ecosystem recovery, and wastewater management [26]. Indeed, the full extent of the consequences of Long COVID may not be apparent for some time yet.

While our study focused on a small group of people in the midwestern U.S., we believe that our findings have far-reaching implications that go well beyond our region. The perspectives articulated by our participants are echoed around the world and reflect the broad impact that COVID has had on planetary health [1,27–29]. The societal and



economic reverberations caused by the pandemic persist, in spite of the World Health Organization's declaration in May 2023 of the end to the public health emergency of international concern [30]. Public health officials and policy makers should be mindful of the long-lasting effects of Long COVID and how these can interfere with achievement of goals set forth by the United Nations for a sustainable and peaceful planet [30], particularly with respect to ending poverty, ensuring good health and well-being for all, promoting work opportunities and economic growth, and reducing inequalities [31].

There are several limitations to our study. First, we recruited participants from a pool of patients from our previous study. Any selection bias that was present in our original study may have been compounded in this longitudinal portion. Second, fewer than half of the original patients interviewed chose to participate in the follow-up interviews, and we do not have any information about the health status of non-participants. Third, our study was conducted at a single academic medical center with a robust Long COVID clinic from which we recruited our participants. Patients attending this clinic may not be typical of all Long COVID patients. Finally, we cannot account for some patients potentially having multiple COVID-19 infections during the study, nor for the impact of vaccination on symptom severity.

## 5. Conclusions

This work gives voice to the lived experiences of patients with Long COVID. It adds to the growing body of work on this condition by adding a personal narrative that complements other data. In addition, considering our results more broadly underscores the need for concerted efforts to mitigate the widespread physical, social, and economic effects of Long COVID worldwide. There is a critical need for continued research on Long COVID so that we can fully support patients and provide the care they need for health and well-being.

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**Data Availability Statement:** Due to participant privacy concerns, the data presented in this study are not publicly available. The data may be requested from the corresponding author.

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