ORIGINAL RESEARCH

# Pulmonary sequelae of COVID-19: An interpretive description study

Cameron Albright*, Jacqueline Limoges, Gwen Rempel

*Athabasca University, Canada*

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## ABSTRACT

The aim of this study was to explore the experiences of adults living with pulmonary sequelae of COVID-19 as a subtype of long-COVID to contribute to pandemic recovery efforts. A qualitative, Interpretive Description design was implemented using semi-structured interviews with 10 participants living with self-reported pulmonary sequelae of COVID-19. Three key findings illustrate the participant experience: (1) the illness burden of pulmonary dysfunction and symptoms, (2) emotional responses to lung damage and symptoms, and (3) navigating the healthcare system. Understanding the burdens associated with the pulmonary subtype of long-COVID such as respiratory symptoms, fatigue, activity intolerance, emotional responses, and inaccessible healthcare can lead to the development and implementation of strategies that support recovery. Further research is needed for a more precise understanding of the experiences of patients with specific pulmonary complications.

**Key Words:** Pulmonary sequelae, Long-covid, Covid-19, Coronavirus, Pandemic, Nursing, Qualitative

## 1. INTRODUCTION

Long-COVID involves symptoms and/or organ dysfunction lasting beyond the expected recovery period, generally, 3 months after the initial infection.[1–3] Long-COVID presents a critical global health crisis with at least 65 million people living with the condition.[4] The most common symptoms include dyspnea, chest pain, arthralgia, fatigue, and cognitive dysfunction.[5,6] Early in the pandemic, post-mortem data highlighted the severe impact that COVID-19 had on the lungs.[7] Many individuals who survived COVID-19, even those with relatively mild cases, exhibited residual pulmonary complications.[8–11] With the ongoing transmission of SARS-CoV-2 and emerging variants, qualitative research can help us bridge the gap between statistical and biomedical research and human experiences leading to a better understanding of health and healthcare needs.[12] Identifying patient experiences with various clinical subtypes of long-COVID can aid in the development of precision healthcare.[13,14] This qualitative study explored the experiences of individuals with long-COVID who had residual lung sequelae to support nurses and allied health professionals in delivering precision healthcare and advancing health system transformation.

### Background

Studies reveal that over half of people hospitalized with COVID-19 exhibited lung abnormalities at three months, six months, and one-year post infection.[15–18] Common respiratory symptoms include dyspnea, cough, and chest pain.[19] Infection with SARS-CoV-2 is thought to trigger ongoing damage-repair processes affecting airway remodeling or fibrosis.[20,21] Deficits in diffusion capacity affect 20%-30% of people who had mild to moderate COVID-19, and 60% of those with severe cases.[22] Turner et al. classified such com-

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* **Correspondence:** Cameron Albright; Email: calbright1@learn.athabascau.ca; Address: Athabasca University, Canada.

plications as non-syndromic long-COVID, marked by organ dysfunction, in contrast to syndromic long-COVID, where no underlying pathophysiological process is identified.[23] Furthermore, Harris describes how people with organ impairment as part of their long-COVID aetiology experience a higher symptom burden than groups without organ impairment.[24]

Understanding the human experiences with different clinical subtypes of long-COVID is important for the development of precision health strategies.[23] Currently, there is a lack of qualitative research that has studied long-COVID with participants experiencing specific sequelae. A systematized review of qualitative research with people experiencing pulmonary sequelae noted that people experienced many challenges that were compounded by dyspnea, fatigue, uncertainty, and the need to navigate a complex health-illness transition.[25] However, additional understanding with a specific focus on pulmonary sequelae was needed to enhance the implementation of effective clinical strategies, policy development, research, and ultimately facilitate precision health for those living with long-COVID. Therefore, this study addressed the following research questions:
1) What are the experiences and healthcare needs of adults with pulmonary sequelae of COVID-19?
2) How do these experiences inform precision health in the pandemic recovery response?

## 2. METHOD

### 2.1 Study design

This study employed Interpretive Description (ID), a qualitative research methodology used to inform nursing and applied practice.[26] ID was chosen as an applied methodology given the important role nurses have in caring for patients with long-COVID to ensure the findings inform practice. Semi-structured interviews by teleconference, telephone, or email were conducted by the first author to explore the experiences of adults living with pulmonary sequelae of COVID-19. Interviews were conducted between January 30th, 2023 and June 15th, 2023. Email responses were used to accommodate participants dealing with dyspnea and fatigue. To explore individual's experiences with this subtype of long-COVID, a reciprocal-interaction philosophy of science, and interview questions adapted from nursing system's theory were used to achieve theoretical scaffolding.[26–28] In the interviews, participants were asked general demographic and introductory questions, such as age, the onset of their initial COVID infection, and the duration of their experience with long-COVID. They also shared self-reports on the nature of their pulmonary sequelae. Subsequently, semi-structured interview questions explored the impact of pulmonary sequelae on their physical, emotional, social, developmental, and spiritual health.

### 2.2 Recruitment

Using critical purposive sampling, participants were recruited from long-COVID support groups on social media platforms.[29] Eligibility criteria included age 18 or above, able to understand English, provide informed consent, and self-reporting of indicators of pulmonary sequelae. These indicators include new or ongoing pulmonary symptoms and functional limitations after the resolution of acute COVID-19 and the need for ongoing supplemental oxygen therapy or changes on diagnostic tests such as chest radiographs, computed tomography, or pulmonary function tests.[30] These indicators were used as a sensitizing framework for the researchers to determine eligibility from the participant's self-reports and no diagnostic data or medical records were needed or accessed, respectively. Informed consent was obtained before data collection, and participants received a $35.00 CAD gift card as a token of appreciation for their time and participation. The study was approved by an institutional Research Ethics Board (Ethics File No: 25083).

### 2.3 Data analysis

The interviews were manually transcribed and anonymized by assigning an identification letter combination (P-A, P-B, P-C, etc.). Reading each interview transcript line-by-line while listening to the recording ensured accurate transcription and was the first step in sorting and organizing the raw data. Using coding procedures in NVivo 11, 548 in-vivo codes were identified in the first inductive coding cycle.[31] In the second coding cycle, in-vivo codes were grouped into 28 categories according to similarities, patterns, or differences to align with the main research questions.[32] This second coding cycle and analysis were directed by constant comparative analysis, in which every piece of data was compared to determine similarities and differences to construct relationships among the data.[26] In the final phase of coding and analysis, three main findings were identified through an iterative process of analytic memo writing and code-weaving and while considering knowledge that was not previously known.[26,33]

## 3. RESULTS

In total, ten (n = 10) participants (see Table 1) within North America joined this study by either teleconference (n = 4), telephone (n = 2), and email (n = 4). The average length of the interviews was 60 minutes. Participants who chose email communication were provided with a document containing interview questions and returned this document to the researcher once completed. All participants had experienced pulmonary sequelae for a minimum of three months and had contracted COVID-19 between February 2020 and December 2022. Using the indicators of pulmonary sequelae as a sensitizing framework to interpret inclusion criteria from participants self-reports,[30] four participants self-reported sequelae which may indicate obstructive complications (hyperinflation, bronchiectasis, asthma, chronic obstructive pulmonary disease), three with restrictive complications (pulmonary fibrosis/scarring), two with embolic complications (pulmonary embolisms), and one with non-specific reductions in lung functioning. It is important to note that diagnostic data was not accessed, and these are intrepretations of participant's self-reports informed by existing clinical knowledge.[34] Three participants were hospitalized in intensive care during their COVID-19 infection and required ongoing oxygen therapy, however, most had not been hospitalized and did not require home oxygen. Half (5/10) of participants were in the age-range of 40-49, followed by 60-69 (3/10), 30-39 (1/10), and 50-59 (1/10). Gender and/or sex data is not reported to protect the privacy and confidentiality of participants who were recruited on social media platforms and to prevent identification. Ethnicity data was not collected.

Participants shared their experiences of transitioning from active, healthy lives to grappling with the physical challenges following COVID-19 infection. Three key findings provide insights that can guide nursing and allied health professionals in diverse care settings. The first finding described participants' high physical illness burden from respiratory symptoms and fatigue and how these impacted their everyday lives. The second finding explains how lung damage and symptoms influenced participants' emotional responses and self-concept. Lastly, the participants detailed their challenges accessing healthcare and how gaps in healthcare practices influenced their overall sense of wellbeing.

**Table 1.** Participant characteristics

| Participant | Age | Initial COVID-19 Infection | Hospitalization During COVID-19 Illness | Need for Ongoing Oxygen Therapy | Participant Reported Pulmonary Complications |
|---|---|---|---|---|---|
| P-A | 40-49 | May 2022 | No | No | hyperinflation of the lungs |
| P-B | 30-39 | Feb 2022 | No | No | blood clots in my lungs |
| P-C | 60-69 | Nov 2021 | Yes, ICU | Yes, previously | pulmonary fibrosis in all lobes of the lungs |
| P-D | 60-69 | Sept 2021 | Yes, ICU | Yes, currently | scarring and damage |
| P-E | 40-49 | Dec 2022 | No | No | bronchiectasis on C.T., with an overlying pseudomonas infection |
| P-F | 40-49 | Feb 2020 | No | No | I have been diagnosed with asthma |
| P-G | 40-49 | Sept 2022 | No | No | recently diagnosed with heart issues, and COPD |
| P-H | 50-59 | Dec 2021 | No | No | pulmonary function test was down to 67 |
| P-I | 60-69 | Sept 2021 | No | No | Blood clots in lungs |
| P-J | 40-47 | Oct 2021 | Yes, ICU | Yes, previously | they saw definite it was pulmonary fibrosis |

*Note.* ICU = intensive care unit; C.T. = computed tomography; COPD = chronic obstructive pulmonary disease

### 3.1 Finding 1–The illness burden of pulmonary dysfunction and symptoms

Participants vividly contrasted their pre-COVID vitality, marked by vigorous cardiopulmonary endurance, with their post-COVID realities of severe physical limitations. While some participants reported cognitive impairments like "brain fog", the predominant burden they faced centered on the pulmonary system and respiratory symptoms. This participant poignantly described the drastic change:

*P-H: Physically, I was in shape... going to the gym 5 to 6 times a week... doing a lot of sports... hiking, canoeing, biking... and now, it's been 15 months, and I can only walk slowly.*

Dyspnea and coughing emerged as the most troublesome symptoms for many participants. They reported the need for focused regulation of breathing during physical activity and even while at rest. Coughing and impaired airway clearance were more commonly reported by participants with obstructive complications like bronchiectasis, chronic obstructive pulmonary disease (COPD), and asthma. These participant quotes illustrate these experiences:

*P-B: My breathing is just absolutely in the trash, it's really hard to do anything. [. . . ] that's one of the major things I've been having a really, really hard time with.*

*P-E: . . . the coughing. . . I can't stop. [. . . ] It's also a pretty productive cough, which is awful. [. . . ] mucus plugging all through the lungs.*

Several participants described the inability to fully expand their lungs with painful breathing or chest discomfort which made breathing exercises challenging due to deep visceral pain. Furthermore, participants described how fatigue and activity intolerance often coexisted with respiratory symptoms, affecting overall well-being and the inability to plan future activities. The following participants shed light into these burdens:

*P-B: my diaphragm hurts [. . . ] I guess there's just a deep pain, like, in my lungs [. . . ], deep breaths that are supposed to, quote, 'help you', do not help me. They are very painful.*

*P-G: [...] pressure on the chest, struggle to breathe, winded easily, coughing continues all day, fatigue, significant reductions in exercise and activity.*

The requirement for oxygen therapy was a common experience among participants following hospitalization. Participants described how their need for oxygen therapy was discovered following hospital discharge and during community rehabilitation:

*P-J: I came home January, the end of January 2022, and I wasn't requiring oxygen. But you know, my breathing was extremely laboured... while I was in the rehab, they put the oximeter on my finger all the time, and I would always drop into the low 80s while walking.*

The impact of fatigue was significant, and many participants experienced disruptions to their sleeping patterns, with hypersomnia being common, as described by these participants:

*P-A: I could go to bed and sleep like the full 12 hours. [...] it's helped me sleep better, but like, to the point where, you know, I don't really actually need, I don't think I need that much sleep.*

*P-H: I'll stay in bed in the morning. I have a hard time to get up, so I'll stay in bed till 9:30-10:00. I'm in bed at 8:00 o'clock at night, and in the afternoon if I am tired, I'll just lie down on the couch and rest there for a bit.*

Oftentimes, extended periods of sleep did not alleviate fatigue. Many tried to push through their fatigue in hopes of recovery, but as they recognized the unique nature of this fatigue, they shifted this approach, realizing that striving for stamina only exacerbated their symptoms.

*P-J: . . . I just gotta get stronger, I got to push myself; but truly, no, that's not how you do it when you have this.*

The complex interplay between respiratory symptoms, fatigue, and activity intolerance was especially evident during PFT when the exertion required intensified their symptoms and fatigue. For some, the forceful breathing during PFT induced illness that lingered for days afterwards, as described by the following participant:

*P-A: I had a heck of a time in there [. . . ], I was actually sick for a few days after that, just all of this inhale and exhaling I was doing for those couple of hours, I did get really sick.*

Participants also described the residual effects from life saving measures of intubation and prone positioning. Three participants who had severe COVID-pneumonia or acute respiratory distress syndrome (ARDS) during their COVID-19 infection required tracheal intubation. These three participants vividly recounted how tracheal intubation led to pronounced changes in their voices, transforming a familiar part of themselves into an unrecognizable sound. One participant described moments when their voice would abruptly falter, leaving them temporarily voiceless:

*P-C: Following intubation, it had come back very gradually and did not sound like my voice at all. [...] I would be in a middle of a sentence and my voice would completely shut down for a few minutes to a few hours.*

In addition, participants shared the enduring physical challenges stemming from being placed in the prone position during treatment for COVID-19. One participant detailed ongoing muscle weakness, back and shoulder issues, and meralgia paresthetica:

*P-D: [...] the proning, you know, there's issues with that later. [...] I was proned, and because the muscles don't support the bone structure and the body, I've got some back issues and some shoulder issues just because of the way the body is positioned and meralgia paraeshetica in my legs, so I'm numb from my knees.*

The illness burden was primarily driven by a range of pulmonary complications and significant changes to cardiopulmonary health. The central burden arose from respiratory symptoms, which were further compounded by severe fatigue and activity intolerance. Participants with obstructive complications (COPD, bronchiectasis, asthma) more frequently described the burden of persistent coughing, and those who had experienced intensive care treatment had additional burdens of the lasting effects from these interventions.

### 3.2 Finding 2-Emotional responses to lung damage and symptoms

Participants shared their emotional journey of grappling with the profound shifts in their physical health and how these

changes deeply affected their sense of self, purpose, and emotional well-being. The loss of cherished abilities which were once central to their identity carried a heavy toll. This participant quote illustrated this experience:
*P-D: So, emotionally it's, I think, the hardest part. [. . . ] I can't sing. . . and that, well, that was my vocation, is my vocation. [. . . ] it's those times when I've been sitting at [the] piano listening to a vocalist and I break out crying without them knowing. [. . . ] there's that grief in it and knowing that this has changed me.*

For some, these losses became the most formidable challenge and a heavy emotional burden, leaving them with a sense of emptiness, sorrow, and a profound feeling of isolation and loneliness. These struggles were marked by a grieving process, where relinquishing what was once cherished proved particularly distressing. They described instances where they grappled with an internal conflict between their pre-COVID selves and their current identities. Moreover, due to the energy depletion they experienced, finding alternative sources of joy seemed elusive and daunting. This participant quote illustrated the experience:
*P-G: It's soul crushing to know those days are likely done. [. . . ] It's sad to give up all the things that brought you joy. . . and no energy or enthusiasm to try and find alternatives because everything else just isn't as good or worthwhile. [. . . ] I am largely navigating this all on my own.*

Participants, especially amongst those living with obstructive lung complications, such as bronchiectasis, COPD, and secondary bacterial infections described living with fear of respiratory failure. These participants described how they were haunted by anxieties about potential respiratory failure and mortality as they witnessed the decline of their respiratory health. The persistence of bacterial infections fueled their fears as this was perceived as an indicator of health instability and further lung damage. The following participant describes these challenges:
*P-G: Also, long infections that will not go away. Was on antibiotics for over 3 straight months, sometimes 2-3 at a time. [. . . ] I have bouts of depression, anger, frustration. I am scared about the reduction in life expectancy as a result. I worry about knowing that I will die of suffocation and that it will be long and painful.*

These participants were apprehensive about the prospect of future clinical interventions such as intubation and bronchoscopy. One participant contemplated advanced care planning because their bronchiectasis was understood to be progressive. This participant described a profound sense of unease regarding their future well-being and the lasting impact of bronchiectasis, which left them with compromised lung function and a heightened vulnerability to recurrent infections and further lung damage:
*P-E: I worry about what it means for my future. [. . . ] I'm going to be intubated in the future, like, that was always the scariest part. . . it wasn't even necessarily dying, it's the things that come with being sick. [. . . ] it's getting scoped or bronched. [. . . ] The bronchiectasis is permanent, and that's the damage that I'll be at a new baseline for, and that also puts me at a higher risk for lung infection because I can't clear my lungs. [. . . ] just knowing that I have damage that holds on to bacteria which creates more damage. . . I'm nervous about what my life is like, and when I look at research, because I do that, which I probably shouldn't. . . like, most people with bronchiectasis die of respiratory failure. [. . . ] I struggle because I don't know who will be my health care agent.*

Some participants expressed fear of reinfection with SARS-CoV-2, which they worried could further deteriorate their compromised pulmonary status. One participant described this fear as follows:
*P-A: [...] before I got COVID I was really, really healthy and like I never got sick. [...] And so, when I got sick after my breathing test, I was worried. [...] I thought I had COVID again. [...] And what happens now? Cause my lungs are already bad.*

These concerns led participants to prioritize stringent measures to ensure their safety such as environmental cleanliness with a particular focus on air quality. Masking in public settings remained a steadfast practice for many participants, reflecting their commitment to safeguarding their respiratory well-being. Adequate ventilation took on heightened importance for some as they sought ways to mitigate the risk of exposure to the virus, as described by the following participant:
*P-E: I have permanent lung damage from COVID... I still wear a mask when I got out in public. [...] One of the things that I feel like no one ever talks about is ventilation. [...] I feel like that is something that is completely ignored in the spaces I'm in.*

Some participants described emotionally taxing experiences, where respiratory symptoms, notably coughing and laryngeal changes caused shame and embarrassment. These emotional responses illustrated the compounding of physical symptoms and how these triggered distressing encounters with other people. Participants described how the impact of coughing, despite wearing a mask to mitigate disruption, drew unwanted attention and unsympathetic comments from others. This unwarranted scrutiny left the following participant ashamed:

*P-F: I was at the movie theatre the other day wearing my mask but coughing. People turned around and glared at me consistently making snide comments. [...] I was so ashamed and felt like I was ruining other people's recreation and leisure that I decided it was easier to leave than stay.*

This quote further highlights the difficulties of unpredictable symptoms in social settings and feelings of embarrassment:
*P-C: Losing my voice was difficult, emotionally. It happened without any warning. As I was ordering food in a restaurant a waitress became irate and offended with me as I suddenly lost my voice. When she came back later, I apologized and explained I could not control it. The people with me were also embarrassed.*

Despite these challenges, participants exhibited remarkable strength and resilience. Some began to appreciate the ordinary moments in life more deeply, while others found solace in their faith. By redirecting their perspective, they managed to reconcile their altered health status and reframe their outlook toward elements they could control, thereby devising strategies to maintain their health within their existing limitations. These participant quotes illustrate this approach:
*P-A: … I'm trying to look at the positive, I'm a positive person, so I try to see the positives in situations. So yeah, it's unfortunate that I did get it, but like I said, I'm trying to do the best with what I got.*
*P-J: … the scarring is there permanently, it's not ever going to go away… and my lung function is at 69%... but I can increase not the lung functionality, but what I can do with what I have.*

Participants grappled with a substantial emotional toll as the illness burden led to grief and sadness over the loss of their prior abilities and self-concept. Those with obstructive complications and secondary infections experienced fears of disease progression and respiratory failure. Concerns about re-infection with SARS-CoV-2 loomed large and created vigilance with hygiene and mask wearing. Participants tried to adapt by shifting their focus to a more positive outlook, aiming to maximize their abilities within these constraints.

### 3.3 Finding 3–Navigating the healthcare system

Participants detailed frequent challenges arising from their experiences accessing healthcare. They described their struggles to obtain a diagnosis and how their physical symptoms were dismissed by healthcare providers. The significant lack of coordinated care made navigating the system to receive specialized care very difficult. Participants also expressed concern regarding societal stigmas and the tendency to downplay the existence of long-COVID.

Many participants expressed disheartening experiences that eroded their trust in healthcare providers and threatened their sense of dignity. These situations arose when the underlying physiological factors responsible for their symptoms were neither recognized nor properly investigated. Instead, some participants were met with superficial expressions of encouragement, unrealistic optimism, and false hope. The following participant described the feeling of being misled and disheartened:
*P-E: She saw the read of the x-ray, the initial x-ray with the pulmonary nodule, and she said [. . . ] 'you're going to go for C.T. and it's going to be nothing' [. . . ] it's false hope and it's not based on anything.*

Some participants felt that the stigma of having contracted COVID-19 in the first place and then having ongoing symptoms impacted the way healthcare providers interacted with them. Additionally, they attributed the societal view of long-COVID as psychosomatic as influencing how healthcare providers interacted with them. One participant offered suggestions to reframe healthcare providers attitudes:
*P-F: Rather than first trying to explain long-COVID as a mental health issue, first look towards what the physical causes are and do so with compassion, patience, and understanding.*

Given the pervasiveness of these interactions within healthcare systems, seeking care for acute cardiopulmonary symptoms proved challenging. These gaps led to diagnostic errors of omission, including the failure to investigate underlying pulmonary complications that later became apparent as a contributor to their long-COVID aetiology. The following participant quote described the experience:
*P-C: The shortness of breath, chest pain, and cough went untreated at emergency visits in the hospital. [. . . ] My doctor admitted being unknowledgeable about COVID and refused to prescribe the oxygen I needed and did not refer me to a respirologist, nor a referral for a scope as promised.*

Many participants described how their lung damage went unnoticed and untreated by healthcare providers. Many revealed delays in receiving a diagnosis and how, for some, a diagnosis occurred incidentally during radiological assessments for concurrent chronic illnesses or through participation in long-COVID clinical trials. Participants expressed concern that diagnostic delays and their lack of awareness about the extent of lung damage hindered effective self-health management and contributed to further health deterioration. Other participants described how they only received attention when they reached a state of acute urgency. The following participant described the onset of severe lung pain which prompted them to seek emergency care:
*P-B: I ended up rushed to the hospital with severe pain in my lungs to a point where I was screaming in the waiting room.*

Many participants were blindsided by the persistent symptoms they experienced and described how they were not given any forewarning that this could occur as a result of infection by COVID-19. Even participants who had lengthy stays in intensive care units during their initial COVID-19 hospitalization said that no one spoke to them about this possibility. The following participant sheds light on this experience:

*P-J: … it didn't even come to my thoughts that maybe my lungs were really damaged, honestly. […] I've probably been doing so much damage, you know, like starving my body of oxygen.*

Some described dehumanizing encounters during pulmonary function testing (PFT), where their compromised health and limitations were disregarded or attributed to a perceived failure to follow instructions. Furthermore, for those who sought care in emergency departments, they relayed encounters that lacked compassion or willingness to grasp the seriousness of their condition. The following participants described what happened during these interactions and how these experiences left them feeling upset:

*P-F: … was told I was not following direction because that was the only feasible reason for the RT for why the test results were consistently inconsistent […]. She told me I would go to the bottom of the 4-month list, I should 'go to therapy and learn how to follow directions' […] and was told I should 'talk to someone about my inability to follow basic coaching'.*

*P-B: … the first nurse that tried to give me the I.V. kind of just told me that, you know, [...] maybe I should start acting like an adult and buck up. […] I was pretty upset.*

Participants often faced barriers to specialized care from healthcare professionals with expertise of long-COVID, such as pulmonologists. This led some to take matters into their own hands and actively pursue the care they needed. However, this self-initiated pursuit added an extra layer of burden to their already challenging experiences, as described by the following participant:

*P-D: I had to pursue it… I really did. […] I had to ask for physiotherapy. I had to ask for a lung specialist. I had to ask for further testing. […] I had to ask for all that.*

For those who managed to secure referrals, they encountered extended waiting periods for appointments. These waiting periods were characterized by uncertainty and ongoing suffering which were exacerbated by the lack of resources available to manage their health. This participant quote detailed this experience:

*P-G: Diagnosed in early March with COPD, first available appointment to see a pulmonologist anywhere in 200 miles is August 11, 2023! So, knowing you have 6 more months to suffer with no treatment, nothing to ease the discomfort, answer questions, or help with the anxiety is tough.*

Participants who did receive specialized care reported notable improvements in their physical well-being and coping with symptoms. Pulmonary rehabilitation and education played a crucial role in enhancing their quality of life and capacity to manage their illness effectively, as described by the following participant:

*P-J: … the first hour was classroom education on your lung disease. So, they were educating us on multiple things; sleep, nutrition, depression, how your lungs function, how to cope, how to take certain medications, like if you have an inhaler, all stuff like that. And then the second half we go into the gym, and it was basically walking, a lot of walking and resistance training, trying to build up your muscles. […] I've progressed unbelievably in these last four or five months than I did in that whole last year, so it really was beneficial.*

Another participant who was cared for by a specialized nurse practitioner was offered treatment with a budesonide inhaler, which resulted in the first relief of their pulmonary symptoms and activity intolerance:

*P-B: When I do take it [budesonide inhaler], I do find that I'm able to walk for long periods of time, like just longer than I usually would. So, it's kind of helped with the opening up my lungs.*

The contrast in experiences from those who managed to access specialized care and those who struggled to have their needs met is poignant and illustrates the potential for health system reform.

## 4. DISCUSSION

Participants in this study were specifically recruited because they had pulmonary sequelae as a subtype of long-COVID. Participants described a high burden of illness from lingering symptoms that restricted their activities of daily living and a high emotional toll which generated uncertainty and negatively impacted their sense of self. Interactions with the healthcare system did not meet their needs, and included interactions that negated their physical symptoms and that perpetuated stigma that long-COVID was a psychosomatic condition. In this discussion, we explore these findings to inform clinical practice and future research.

The physical symptoms outlined by the participants align with those documented in existing literature, underscoring the significance of these symptoms.[25,35] This alignment validates the persistent fatigue, dyspnea during daily activities and at rest, chronic coughing, impaired airway clearance, and pain reported by the participants. By narrowing the focus of this study to individuals with the pulmonary subtype of long-COVID, rich symptom descriptions can assist healthcare providers to recognize symptoms leading to more effective patient interactions and healthcare interventions. Furthermore, the three findings can provide understanding that can enhance communication and the development of a shared language between the patient and healthcare provider surrounding the experience of the illness. Suliman et al. recommend that clinicians maintain a heightened level of clinical suspicion for pulmonary complications of COVID-19.[36] Learning about the symptom burden from the patient perspective can assist healthcare providers to accurately assess patients and engage with them in ways that promote their well-being.

Participants vividly expressed emotional responses, including grief, a sense of losing one's identity, and the ever-looming fear of respiratory failure which exacerbated their struggles and instilled a sense of profound uncertainty. Albright et al. underscored the impact of COVID-related lung damage on the uncertainty associated with the illness.[25] Our study expands on this, shedding light on how physical complications and symptoms contributed to the emotional turmoil experienced by individuals with long-COVID. The assessment and management of uncertainty is a crucial aspect of nursing knowledge.[37] In particular, participants grappling with obstructive complications like bronchiectasis and COPD, along with secondary bacterial infections, perceived their conditions as progressive, with concerns revolving around the ominous prospect of suffocation and respiratory failure. This finding represents an undocumented facet of their experiences and holds important implications for healthcare providers. It can prompt providers to explore concurrent diagnoses, physical symptoms, and the patient's unique appraisal of their illness, and as a way to engage in meaningful patient supports. Future research should concentrate on refining the understanding of the distinctive challenges faced by individuals with specific pulmonary complications and evaluating healthcare strategies aimed at addressing their specific needs.

Albright et al. documented how a diagnosis of pulmonary sequelae could validate the condition and facilitate access to care along the health-illness continuum.[25] Our research shed light on the challenging journey to diagnosis and the struggle to articulate symptoms in a manner that healthcare providers could truly comprehend. Implicit assumptions may cause healthcare providers to disproportionately emphasize the psychological aspects of long-COVID, thereby exacerbating stigma and missed opportunities to provide care.[38,39] This study underscores the adverse consequences of downplaying physical repercussions of long-COVID. These encounters compromised dignity, contributed to undetected lung damage, created barriers to accessing specialized healthcare, ultimately leading to prolonged suffering. This misalignment can be attributed to the absence of shared language or conceptual frameworks to guide clinical understanding, contributing to feelings of isolation and a lack of validation.[40] Our study contributes to the evolving development of such shared understandings, which clinicians can utilize to gain a deeper understanding of the complex illness burden and the emotional responses linked to pulmonary sequelae to facilitate the delivery of relational care.

Participants in this study recounted the absence of support or guidance from the healthcare system to help them comprehend and navigate their diagnosis. The absence of established care pathways and screening measures in both community and hospital settings, along with the prevailing misperception that long-COVID is primarily psychosomatic, were recurring concerns described by participants. The study deepens our knowledge of previous findings regarding the lack of treatment options and the unsettling uncertainty surrounding the trajectory of the disease.[41,42] While addressing these barriers remains a difficult task, our study underscores the importance of establishing targeted care pathways to enable early detection of pulmonary complications. Dennis et al. urges greater awareness of organ dysfunction in the general population.[43] They recommend the adoption of public health policies designed to identify individuals with specific subtypes of long-COVID, enabling swift diagnosis and the facilitation of appropriate referrals.[43] Our study provides insight into the adverse outcomes, such as undetected lung damage, worsening health status, and difficulty accessing specialized treatment that participants faced in the absence of these secondary prevention measures.

Those who received the care they needed experienced enhanced physical abilities, respiratory function and activity tolerance, quality of life and reduced symptoms. They also explained how they were more informed about their pulmonary complications and their ability to effectively adapt and engage in self-health management. Pulmonary rehabilitation exhibits substantial promise to improve pulmonary function, activity tolerance, and reduced fatigue for individuals living with long-COVID and this study illustrates the importance of introducing these programs into care pathways.[44–47] Participants described how they were trying to reframe their challenges by finding possibilities and optimism. It was encouraging to hear how participants who did receive specialized care benefited and how this care helped them on a path to recovery. These findings demonstrate the potential and positive impact from health system transformation.

### 4.1 Rigor and reflexivity

The study maintained rigor and reflexivity through current standards used in ID studies.[26] To ensure that the researcher was aware of how their personal beliefs and values influenced the process and outcomes of the research, the investigator employed reflexivity through journaling. Epistemological integrity was sustained through a justifiable line of reasoning and analytic logic with a documented audit trail. Representative credibility, another aspect of rigor, was achieved by capturing the experiences of participants using critical case purposive sampling. Lastly, interpretive authority, which emphasizes the importance of the data informing conclusions, was sought throughout the entire research process through collaboration amongst the research team.

### 4.2 Limitations

This study has some limitations to consider. First, participants self-identified to meet inclusion criteria, and diagnostic documentation wasn't mandatory, which limits our full understanding of participants' physiological complications. However, it does respect participants' perceptions and interprets results through this lens. Second, online recruitment and data collection methods may have excluded those without internet access. Third, although email communication allowed for flexibility in participation, the capacity to inquire, probe, and obtain a detailed description of the experiences of participants using this method was limited.

## 5. CONCLUSIONS

This study illuminates the significant symptoms and illness burden from the pulmonary subtype of long-COVID and describes the impact of gaps in health services. The rich descriptions of the varied symptoms and emotional responses highlights the complex nature of this subtype of long-COVID. By developing shared understandings of the experiences and challenges faced by people with pulmonary sequelae, healthcare providers have opportunities to improve health services. Future research is needed to focus on the experiences of people with specific pulmonary sequalae and to measure the impact of new healthcare strategies on patient health outcomes.

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## AUTHORS CONTRIBUTIONS

CA, JL, and GR contributed to the study design, data analysis, and writing of the manuscript. CA was responsible for data collection. All authors approved the final manuscript.

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## CONFLICTS OF INTEREST DISCLOSURE

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## DATA SHARING STATEMENT

No additional data are available.

## OPEN ACCESS

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