

ATHABASCA UNIVERSITY

PULMONARY SEQUELAE OF COVID-19: AN INTERPRETIVE DESCRIPTION

BY

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Approval of Thesis

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Dedication

This thesis is dedicated to the memory of Dr. Li Wenliang, an early whistleblower who raised alarms about the COVID-19 outbreak in Wuhan, China in December 2019. Dr. Li's alerts to his colleagues expressed deep concern about a potential epidemic. However, he was reprimanded for disrupting social order. Tragically, Dr. Li contracted COVID-19 while treating patients and passed away at the age of 34, leading to public outrage and global discussions on freedom of speech and transparency. He remains an enduring symbol of courage.

Acknowledgement

I am immeasurably grateful and indebted to my thesis co-supervisors, Dr. Jacqueline Limoges Ph.D., RN and Dr. Gwen Rempel Ph.D., RN for their support as a graduate student, and most importantly, as a human being during this project. I am a better nurse because of my privilege to learn from you both.

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I want to express my gratitude to my family, friends, and colleagues for their unwavering support throughout the years. Both the challenges of the pandemic and the demands of graduate education were isolating at times, but your presence has kept me connected. Thank you.

Abstract

This thesis, a series of manuscripts, advances nursing knowledge of pulmonary sequelae as a subtype of long-COVID. A systematised review of qualitative research brought forth valuable insights for clinical nursing practice, while also identifying knowledge gaps. Previous qualitative research had taken a broad approach to long-COVID, but the changing landscape demanded a more focused understanding of patient experiences given distinct subtypes associated with specific body system dysfunctions. I devised an innovative study protocol that outlined philosophical and methodological considerations for engaging those with pulmonary sequelae of COVID-19 in qualitative research. Findings characterized participant experiences of symptoms, emotional responses to lung injury, and healthcare access challenges. The knowledge acquired has the potential to shape nursing practice, guide policy development, and inform further research. The manuscripts within this thesis contribute to a deeper understanding of patient experiences within the context of this long-COVID subtype and propel methodological discourse for further research.

Keywords: Pulmonary sequelae, long-COVID, COVID-19, coronavirus, pandemic, nursing care, transitions, uncertainty, symptoms

Preface

In early 2020, I vividly recall holding a test report that read "SARS-CoV-2 POSITIVE" as my hands trembled. The uncertainty surrounding COVID-19 was palpable, and the ensuing three years tested me in unimaginable ways. It is impossible for me to revert to my pre-pandemic self. As a new nurse with 1.5 years of experience, I was unprepared for the immense human suffering and haunting images I would encounter along the devastating path of COVID-19. Fear and exhaustion prompted me to channel my efforts into a singular mission: alleviating the human suffering inflicted by COVID-19.

These early career experiences profoundly influenced my identity as a nurse and as a human being. Those affected by COVID-19 and its enduring consequences will forever hold a special place in my heart, clinical practice, and scientific pursuits. My first encounter with a patient with COVID-19 was during the convalescent phase, witnessing severe lung damage and lasting impairments. This contrasted with my colleagues who initially cared for acute or critically ill patients, giving me early awareness of the significant morbidity that could follow COVID-19.

As the pandemic unfolded, I cared for individuals in various acute settings, witnessing their rapid deterioration to respiratory failure due to COVID-19 pneumonia. Months later, I encountered patients requiring nursing care for ongoing COVID-19 complications, leading to severely impaired pulmonary function, immobility, and psychological distress. Throughout my work in acute and community settings during these years, I realized the scarcity of evidence to understand the complex subjective experiences and responses of individuals living with COVID-19's pulmonary sequelae. This realization served as the driving force behind the focus of this thesis.

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Chapter 1. Introduction

Background

As we find ourselves almost four years into the pandemic, the persistent nature of COVID-19-related symptoms has undeniably evolved into a significant public health concern, impacting both individuals and society at large (Garg et al., 2021; Halpin et al., 2021; Rando et al., 2021). To address this challenge, precision health initiatives are instrumental to the categorization of these sequelae into clinical subtypes, providing tailored and more effective treatment strategies (Deer et al., 2021; Estiri et al., 2021). Among these subtypes, pulmonary sequelae have emerged as a focal point due to the susceptibility of the lungs to long-term consequences (George et al., 2020; Scelfo et al., 2020). The evidence of lung damage among individuals recovering from COVID-19 has garnered global attention, and pulmonary sequelae are currently recognized as evolving clinical phenotypes, characterized by lasting alterations in lung tissue and the development of fibrotic lesions (Ali & Ghonimy, 2021; Hama Amin et al., 2023).

Nurses, in their diverse practice settings, continue to bear an important responsibility of caring for patients with COVID-19 sequelae (Maxwell & Radford, 2021). These sequelae, particularly in the pulmonary system, can necessitate additional oxygen support, reduce functional capacity, and impede pulmonary function (Beauchamp et al., 2022). Despite the ongoing clinical care provided by nurses, the subjective experiences of individuals living with pulmonary sequelae as a subtype of long-COVID remain inadequately understood, with limited qualitative evidence available to offer a comprehensive understanding. The importance of nurses understanding the diverse subtypes of COVID-19 sequelae for delivering high-quality care is gaining recognition (NHS, 2022). Qualitative research stands as a fundamental source of

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knowledge that shapes nurses' critical thinking (Daly, 2007; Thorne, 2009). Therefore, the generation of qualitative data is imperative, as it is essential for achieving precision in healthcare, and without it, precision health initiatives remain incomplete (Myroniuk et al., 2021).

Aim and Purpose

The aim of this thesis has been threefold, consisting of a systematised literature review, a qualitative research protocol, and original research, all geared toward advancing our understanding of pulmonary sequelae of COVID-19 and improving patient care. These contributions to the ongoing discourse on long-COVID subtypes and qualitative research stand to benefit both those affected by this condition and the healthcare professionals dedicated to their care. Together, these three manuscripts represent a significant step toward addressing the complex and multifaceted issues related to COVID-19 sequelae.

Purpose of the Manuscripts

Manuscript 1: Living with pulmonary sequelae of COVID-19 and the implications for clinical nursing practice: A qualitative systematised review.

The first manuscript is a systematised review focusing on the available qualitative research on people with pulmonary sequelae of COVID-19. This work served to accomplish the three main goals when beginning a qualitative interpretive description study: (1) premises the study in the body of existing knowledge; (2) provides a critical evaluation of what is known and what is not; and (3) provides an interpretive critique on the strengths and weaknesses of the body of knowledge in general (Thorne, 2016). To contribute to the growing knowledge base on the long-term consequences of COVID-19 this literature review is published in the peer-reviewed Journal of Clinical Nursing (<https://doi.org/10.1111/jocn.16664>)

Manuscript 2: A Qualitative Research Protocol for Studying Pulmonary Sequelae of COVID-19

The second manuscript is the study protocol applied in the primary study (manuscript 3), to contribute to the discourse on long-COVID subtypes and qualitative research. The article outlines ontological, epistemological, and methodological choices, some which have not yet emerged in qualitative research of long-COVID, underpinning the study and shedding light on their influence on the research design.

Manuscript 3: Pulmonary Sequelae of COVID-19: A Qualitative Interpretive Description Study

The third manuscript documents the findings of the primary study. This study answered the 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?

Definition of Key Terms

Long-COVID

Long-COVID refers to the presence of symptoms that exceed the expected timeframe of recovery from COVID-19 infection (Fernández-de-Las-Peñas et al., 2021). Long-COVID is characterized by fatigue, cough, chest tightness, shortness of breath, palpitations, myalgia, and difficulties concentrating and is the result of organ damage, post-viral syndrome, post-critical care syndrome, or other causes (Raveendran et al., 2021). The taxonomy of prolonged symptoms after acute COVID-19 infection is evolving, and the research community has not yet agreed upon a single definition to describe the phenomenon. The World Health Organization (WHO) classifies long-COVID as occurring within three months from the onset of acute COVID-19 with

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symptoms that last at least two months (WHO, 2021). Long-COVID was termed directly by the population suffering from its effects in early 2020 (Callard & Perego, 2021), and as such it will be used synonymously with term COVID-19 sequelae, when appropriate, throughout this text.

Phenotype and Subtype

A phenotype, also known as an illness subtype, is the readily recognized external manifestations, symptoms, and signs of illness (Schulze & McMahon, 2004). It may be difficult to evaluate a phenotype because an illness may be poorly described or quantified, contain underlying disorders, each with a distinct genetic and/or environmental influence, or have unidentified environmental components (Wojczynski & Tiwari, 2008). The Human Phenotype Ontology (HPO) is a framework for “medically relevant phenotypes, disease-phenotype annotations, and the algorithms that operate on these” (Kohler et al., 2021). By giving the ability to compute across the clinical phenotype, the HPO is used to enable differential diagnoses and translational research (Kohler et al., 2019; Robinson et al., 2015).

Phenotypes and Subtypes of Long-COVID

Understanding the phenotypic distinctions of COVID-19 sequelae provides a path toward greater precision in healthcare initiatives. The novelty of COVID-19, however, means that this body of knowledge is ever evolving. Nevertheless, it is understood that COVID-19 sequelae are characterized by diverse symptoms spanning multiple organ systems including the pulmonary, neurological, cardiovascular, gastrointestinal, dermatological, endocrine/genitourinary, and musculoskeletal systems (Raman et al., 2022). Most recently, the data of 2,256 patients revealed six groups of individuals with COVID-19 sequelae, each with unique profiles of phenotypic abnormalities, including clusters with specific pulmonary, neuropsychiatric, and cardiovascular dysfunctions, as well as a cluster linked to extensive, serious complications and higher mortality

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(Reese et al., 2023).

Pulmonary Sequelae of COVID-19

As a result of pulmonary dysfunction and chronic lung injury, pulmonary sequelae are one of the complicated subtypes of long-COVID (Ali & Ghonimy, 2021; Touman et al., 2022; d'Ettore et al., 2022). The pathophysiological trajectory of pulmonary sequelae is not yet completely understood. However, regardless of the source, it is believed that lung damage results from the dysfunctional repair of wounded lung parenchyma. Upon repeat chest computed tomography (CT), bronchovascular bundle distortion, fibrotic strips, traction bronchiectasis, architectural distortion, subpleural curvilinear atelectasis, and interlobular septal thickening were CT results that are suggestive findings of pulmonary sequelae (Ali & Ghonimy, 2021). These radiological anomalies may improve over time (Wu et al., 2021), but not for the majority. Even 1 year after COVID-19 infection, most people persisted with chronic pulmonary sequelae (Han et al., 2021) and often experienced prolonged dyspnea, cough, chest discomfort, fatigue, and myalgia (Hama Amin et al., 2022).

Conclusion

The ongoing COVID-19 pandemic has spurred significant global health concerns with the emergence of persistent COVID-19 sequelae. Precision health initiatives, including the study of pulmonary sequelae as a clinical subtype, is underway. However, a dearth of understanding regarding the subjective experiences of patients poses a challenge for nurses involved in their care. Bridging this knowledge gap, qualitative research is pivotal. This thesis advances knowledge with a systematised literature review, a qualitative research protocol, and original research, collectively enriching our understanding of pulmonary sequelae. These contributions

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mark important strides in addressing the multifaceted challenges posed by COVID-19 sequelae, benefiting both patients and healthcare professionals, and informing further research.

Chapter 2. Manuscript 1 - Living with pulmonary Sequelae of covid-19 and the implications for clinical nursing practice: A qualitative systematised review

Abstract

Aim: To synthesize qualitative research on pulmonary sequelae of COVID-19 and identify patient needs and experiences to develop nursing care strategies.

Background: The grouping of pulmonary complications and lung damage has generated the classification of pulmonary sequelae as a subtype of long-COVID. Qualitative research on long-COVID by subtype has not yet occurred. Exploring these patient's experiences and needs can generate knowledge to guide nursing practice.

Design: Systematised review methodology utilized on a purposive sample of published articles and reported using the PRISMA guidelines and checklists. Searched MEDLINE, Cumulative Index to Nursing and Allied Health, and Google Scholar, for English or French articles published from February 2020 to June 2022; qualitative research with adults recovering from COVID-19 with evidence of pulmonary sequelae.

Methods: Established principles for data extraction followed related to data reduction, data presentation, data comparison, and conclusion formulation and verification. Analysis was informed by Thorne's Interpretive Description and extended with Meleis' transitions theory, Mishel's uncertainty in illness theory, and Moore et al.'s holistic theory of unpleasant symptoms. The quality of included studies was assessed Joanna Briggs Institute critical appraisal tool for qualitative research.

Results: Four articles with six pooled participants provided data to yield three main themes: (1) a novel health-illness transition, (2) lung injury and pulmonary fibrosis as antecedent to illness uncertainty, (3) and pulmonary symptoms that are compounded by fatigue and weakness.

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Conclusion: Pulmonary sequelae of COVID-19 confer a unique health-illness transition, uncertainties, and symptoms that can be addressed by theory informed nursing practice.

Relevance to clinical practice: Advocacy, optimizing the nurse-patient relationship, offering up-to-date information, and addressing uncertainty may help patients cope with pulmonary sequelae. Despite a lack of evidence-informed clinical pathways, nurses can support patients to understand novel treatments, support discharge planning and acknowledge the synergistic nature of pulmonary symptoms and fatigue to support health-illness transitions.

No Patient or Public Contribution: This article involved analysis of previously published works.

Keywords:

Pulmonary sequelae, long-COVID, COVID-19, coronavirus, pandemic, nursing care, transitions, uncertainty, symptoms

Registration and protocol: A protocol was not prepared.

What does this paper contribute to the wider global clinical community?

- This systemized review offers nurses a patient perspective of pulmonary sequelae as a novel health-illness transition that contributes to illness uncertainty while the patient's pulmonary symptoms are compounded by fatigue and weakness.
- Advocacy, optimizing the nurse-patient relationship, providing patients and family members with up-to-date information, and addressing uncertainty may help patients cope with pulmonary sequelae, a complex subtype of long-COVID.

Introduction

When the SARS-CoV-2 (COVID-19) pandemic started in early 2020, scientists worldwide accelerated research to understand the virus, develop viable therapies, and create vaccines to mitigate mortality (Martinez-Baz et al., 2021). Anticipating post-viral sequelae, a research priority was to identify risk factors, processes, and possible treatments for post-acute sequelae of COVID-19 (PASC), now commonly referred to as ‘long-COVID’ (McClymount, 2021). Long-COVID is characterized by a complex set of persistent physical symptoms, an unknown prognosis, and lack of definitive treatments. These factors create considerable stress and uncertainty for people with long-COVID and practitioners struggle with clinical management (Cha & Baek, 2021; Martinez-Baz et al., 2021; Kingstone et al., 2020). There is growing evidence that long-COVID has multiple subtypes, each with unique symptoms that may benefit from targeted therapies. Scientific advancements are leading to descriptions of a complex subtype of long-COVID where people experience considerable alterations to pulmonary functioning and ongoing symptoms such as dyspnea (Vianello et al., 2022; Yong & Liu, 2021). Healthcare providers and health systems need to adapt to long-COVID by developing new treatments, care pathways, and supports. Recognizing that people with various long-COVID subtypes will have diverse experiences, an examination and synthesis of the current qualitative research on pulmonary sequelae was done to determine the needs and experiences of people living with this subtype of long-COVID. The findings from the synthesis are interpreted with three midrange nursing theories to provide guidance for targeted nursing care aimed at pandemic recovery and well-being.

Background

A retrospective cohort study of 273,618 COVID-19 survivors estimates the incidence of long-COVID at 57 percent (Taquet et al., 2021). As the cases of COVID-19 climb worldwide, the number of people with long-COVID is rising (Callard & Perego, 2021). People most at risk for developing long-COVID are those who had severe COVID-19, rapid clinical deterioration, acute respiratory distress syndrome (ARDS), and respiratory failure which necessitated ICU treatment (Rai et al., 2020).

A challenge to developing care and treatment strategies for long-COVID is the lack of clarity of pathogenesis and symptomatology (Carson, 2021; World Health Organization (WHO), 2021) and accepted criteria for categorizing chronic symptoms or organ impairment (Yong & Liu, 2021). To address this challenge, the identification of long-COVID subtypes is now underway, providing needed information to diagnose and treat the array of long-COVID symptoms to optimize clinical outcomes (Crook et al., 2021). Based on a semi-systematic review, Yong & Liu (2021) propose six subtypes of long-COVID: (1) COVID-19 multi-organ sequelae that are not severe, (2) pulmonary fibrosis sequelae, (3) myalgic encephalomyelitis or chronic fatigue syndrome, (4) postural orthostatic tachycardia syndrome, (5) post-intensive care syndrome, and (6) medical or clinical sequelae.

Pulmonary Sequelae of COVID-19

Pulmonary sequelae is one of the complex subtypes of long-COVID arising from pulmonary complications and chronic lung damage (Ali & Ghonimy, 2021; Touman et al., 2022; d'Ettore et al., 2022). A meta-analysis including 2,018 participants suggests the incidence of fibrotic lung alterations is 44.9 percent amongst COVID-19 survivors (Hama Amin et al., 2022). Deer et al. (2021) discuss COVID-19 pulmonary sequelae demonstrating altered lung

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morphology and physiology using the Human Phenotype Ontology (HPO). To further describe long-COVID features, again using the HPO and data from electronic health records (EHRs). The HPO is a method of analyzing phenotype data and human genomics to provide a complete description of phenotypic features associated with human illness (Groza et al., 2015; Kohler et al., 2017). The data of 2,256 patients revealed a ‘pulmonary cluster’, known as ‘cluster 2’ amongst six other distinct long-COVID subtypes. Patients in ‘cluster 2’ had significant rates of hypoxemia and coughing (Reese et al., 2023). One-third of patients who recover from severe COVID-19 have fibrotic alterations on chest computed tomography (CT) (Vianello et al., 2022). Consolidation, reticulation, residual ground-glass opacities, interstitial thickening, and fibrotic changes are common (Michelen et al., 2021). Additionally, substantial impairment in diffusion capacity was identified in 23.5 percent of hospitalized patients at six-month follow up (Magdy et al., 2022). Specific risk factors for developing pulmonary sequelae are male sex, advanced age, tobacco and alcohol use, and concomitant conditions such as diabetes, obesity, hypertension, chronic pulmonary, hepatic, cerebrovascular, and cardiovascular illness (Vianello et al., 2022).

These important research findings help clarify the pulmonary sequelae as a subtype of long-COVID which will help guide basic, clinical, and translational research to enhance precision in healthcare interventions. As this is a developing body of knowledge, the taxonomy used to describe COVID-19 pulmonary sequelae is variable. Beauchamp et al. (2021) established criteria for comprehensive pulmonary rehabilitation in light of emerging research. These criteria aim to guide practical treatment initiatives for this population premised on the notion that certain individuals with COVID-19 have specific pulmonary complications (see **Table 1**).

While there is a growing emphasis on biomedical research by subtype to clarify the pulmonary manifestations of long-COVID, the qualitative research remains focused on long-

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COVID in general. Given the growing acknowledgement that long-COVID is not a single disease, the lack of qualitative research exploring experiences by subtype is creating a gap in understanding. To address this gap, a qualitative systematised review was conducted with extracted participant interview data from published qualitative studies to describe experiences with pulmonary sequelae. Until qualitative studies focusing on long-COVID subtypes are conducted, this synthesis can contribute to evidence-informed nursing (Myroniuk et al., 2021) and highlight the unique needs of this population.

Aim

The aim of this systematised review is to synthesize the qualitative research with adults living with pulmonary sequelae of COVID-19 to elucidate patient needs and experiences to generate knowledge for clinical nursing practice.

Methods

Design

Systematised review methodology (Grant & Booth, 2009) was used to analyse a purposive sample of qualitative research on long-COVID that contained participant interview data elucidating to pulmonary sequelae. Procedures established by Whittemore and Knafl (2005) were used, including: issue identification (i.e., pulmonary sequelae as a subtype of long-COVID that needs qualitative knowledge synthesis), literature search, quality evaluation, data extraction to create pooled qualitative findings and data synthesis. Analysis was informed by Thorne's Interpretive Description and extended with Meleis' transitions theory, Mishel's uncertainty in illness theory, and Moore et al.'s holistic theory of unpleasant symptoms. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria (**Figure 1**) and checklist were followed (Page et al., 2021). Risk of bias or misinterpretation was reduced with

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journaling and collaborative writing with co-authors. The review was conducted by the first author in collaboration with co-authors.

Search Strategy and Eligibility Criteria

Research literature from February 2020 to June 2022 was searched using three electronic databases: MEDLINE, Cumulative Index to Nursing and Allied Health (CINAHL), and Google Scholar. A list of search terms, subject headers, and free-text search phrases were joined using Boolean operators and customized for each database: ((*“Severe SARS-CoV-2” OR “Severe COVID-19” OR “Severe 2019-NCOV” OR “Severe COV-19”*) OR (*“SARS-CoV-2 hospitalization” OR COVID-19 hospitalization*)) AND (*“patient experience” OR “lived experience” OR “qualitative”*) AND (*“long-COVID” OR “post-acute sequelae of COVID-19”*) OR (*“pulmonary fibrosis sequelae” OR “pulmonary sequelae”*)). The grey literature was consulted along with manual searching of bibliographic data from included studies.

Inclusion criteria were qualitative studies using participant interviews with adult patients (18 and above) of any sex or gender who were recovering from acute COVID-19 with evidence of pulmonary sequelae following hospitalization. Articles were included if evidence of pulmonary sequelae could be derived from their interview data. Beauchamp et al.’s (2021) explicit criteria for pulmonary rehabilitation after COVID-19 were employed to determine whether participant’s interview data contained evidence of pulmonary sequelae (see **Table 1**). Only subjective criterion expressions from Beauchamp et al.’s (2021) framework were used. Oxygen, lung injury, lung scarring, Xray or CT changes, and fibrosis are examples of keywords that triggered inclusion of participants’ interview data from the articles included in this review. Further inclusion criteria were published in peer-reviewed nursing and allied-health academic journals, theses, or dissertations, were written in English or French. Exclusion criteria were

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studies with no qualitative description of pulmonary sequelae in accordance with Beauchamp et al.'s (2021) criteria, studies which focused on pediatric or obstetric populations, and that were published in languages other than English or French.

Table 1.

Eligibility Criteria

- New or ongoing respiratory symptoms and functional limitations after resolution of acute COVID-19

AND

New or ongoing requirement for supplemental oxygen after resolution of acute COVID-19

OR

AT LEAST ONE OF:

- Persistent radiographic pulmonary abnormality (i.e., Chest X-ray and/ or CT chest demonstrating new/persistent reticular changes and/or fibrosis after resolution of acute COVID-19)

OR:

- Pulmonary function test results demonstrating new/persistent reduction in lung volumes, airflow limitation, and/or reduction in diffusing capacity after resolution of acute COVID-19
-

Note. Adapted from Beauchamp et al. (2021, p. 10)

Results

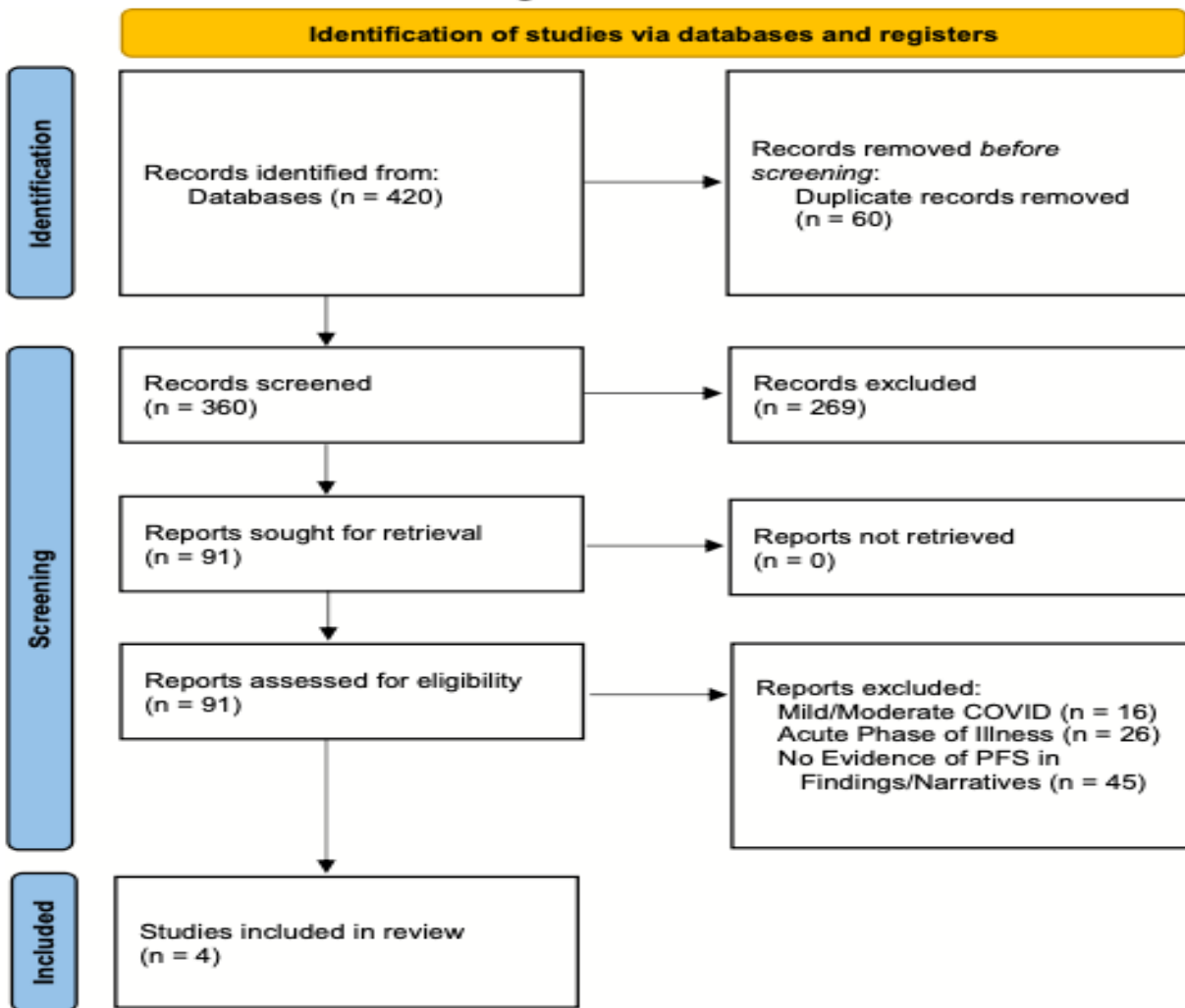
Search Outcomes

A search of electronic databases yielded 420 articles. Sixty duplicates were removed, and the remaining 360 articles were screened by title and abstract using the inclusion criteria, resulting in 91 articles for full-text review, and 87 articles being excluded (see **Figure 1**). The final sample included four articles published between 2020 and 2022. No qualitative studies focused specifically on pulmonary sequelae as a subtype of long-COVID, however, a pooled sample of six participants with evidence of pulmonary sequelae in their interview data was

obtained from the four included studies. While the participant sample is small, pooling the data yielded important qualitative findings on pulmonary sequelae as a subtype of long-COVID.

Figure 1.

PRISMA 2020 Flow Diagram of the Study Selection Process



Quality Evaluation

To assess the quality of included studies in this systematised review, the Joanna Briggs Institute (JBI) critical appraisal tool for qualitative research was used [Appendix A]. Studies were rated as having low, medium, or high quality following the critical appraisal process performed by the first author.

Study Characteristics and Quality

Study locations include China (Guo et al., 2022), Turkey (Kurtuncu et al., 2021), Iran (Khoshnood et al., 2021), and the United States of America (Santiago-Rodriguez et al., 2021). Specified qualitative methodologies included phenomenology, exploratory qualitative design, conventional content analysis, and thematic analysis. Three studies (Guo et al., 2022; Kurtuncu et al., 2021; Khoshnood et al., 2021) were rated as high quality on the JBI quality checklists, and one (Santiago-Rodriguez et al., 2021) received a medium quality rating due to unclear descriptions of their philosophical orientation and missing statements to locate the researcher culturally and theoretically.

Data Extraction and Synthesis

Established principles for data extraction (Whittemore & Knafl, 2005) were followed related to data reduction (i.e., subgroup characterization based on research design, data extraction and coding), data presentation (i.e., displayed as a table), data comparison, and conclusion formulation and verification. Polit and Beck's (2008) literature extraction tool was adapted to record the authors, location, setting, sample, design, methods, phenomenon of interest, and major findings from participant data related to pulmonary sequelae for each study (see **Table 2**). Participants characteristics of pulmonary sequelae were pooled and described (see **Table 3**). Pooled data were analyzed using interpretive description approaches (Thorne, 2016), to give meaning in context for nursing practice. Interpretive description was employed to generate knowledge relevant to nursing practice. Interpretive description is a pragmatic approach to guide research for nursing care delivery with unknown or emerging phenomena for which little evidence-informed knowledge exists (Thorne, 2016). Analysis of the pooled participant data yielded four themes.

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Table 2.

Summary of Included Studies

Authors, Year/JBI Rating	Location/Setting/Sample	Study Design/Methods	Phenomenon of Interest	Major Findings Characteristic of Pulmonary Sequelae
Guo et al., (2022) High [9/10]	Wuhan, China/Sino-French New City Branch of Tongji Hospital <ul style="list-style-type: none"> • Sample size: 16 • Mean age: 47.8 • Women: 10/16 (63%) 	Phenomenological methodology: semi-structured interviews	Post-discharge experience of COVID-19 survivors	Of 16 participants, three participants indicate lung injury or fibrotic development, multiple pulmonary symptoms, use of oxygen therapy, and uncertainties along an unknown illness trajectory.
Kurtuncu, et al. (2021) Medium [7/10]	Bartın, Turkey/Zonguldak Ataturk State Hospital <ul style="list-style-type: none"> • Sample size: 18 • Age: range 39-77 • Women: 4/18 (22%) 	Exploratory qualitative design: semi-structured interviews	Experiences of COVID-19 patients in intensive care units and after discharge	Of 18 participants, one described developing lung injury and expressed awareness of these effects secondary to COVID-19 and that it requires one to learn how to cope.
Khoshnood et al., (2021) High [8/10]	Kerman, Iran/Afzalipour Hospital <ul style="list-style-type: none"> • Sample size: 17 • Age: range 28-80 • Women: 8/17 (47%) 	Qualitative conventional content analysis: semi-structured interviews	Experiences of living with COVID-19 following intensive care treatment	Of 17 participants, one participant described lung damage and its effect on overall functioning leading to weakness and uncertainties about the future.
Santiago-Rodriguez et al., (2021) Medium [7/10]	Northern California, USA/ Single Centre <ul style="list-style-type: none"> • Sample size: 24 • Median age: 49 • Women: 37.5% • Caucasian: 66.7% • Latinx/Hispanic: 50% • Sub sample of hospitalized participants: 9 	Qualitative thematic analysis: semi-structured interviews	Experiences of patients with a varying clinical spectrum of COVID-19 (asymptomatic to severe illness) during recovery, including participants living with HIV	Of 24 participants, one participant described their concern over “complications with the scar tissue” leading to the use of new pharmacotherapies and self-monitoring strategies

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Table 3.

Pooled Participant Characteristics

Authors	Participant	Age	Gender	Clinical Classification	Comorbidities	Pulmonary Sequelae Connection in Participant Interview Data
Guo et al. (2022)	H14	44	Male	Severe	Diabetes	Uncertainty about prognosis of lung fibrosis
Guo et al. (2021)	H12	50	Female	Severe	Hypoglycemia, hypotension	Multiple cardio-respiratory symptoms; inconsistency between diagnostics and symptoms; lack of healthcare support; complicated physical recovery
Guo et al. (2021)	H16	52	Female	Mild	Nephrolithiasis, COPD	Uncertainty about implications for poor CT results; lack of healthcare support
Kurtuncu et al. (2021)	P12	67	Male	Severe	Diabetes, hypertension	Adaptation required due to the development of lesions in the lungs
Khoshnood et al. (2021)	P5	N/S	N/S	Severe	N/S	Concern about persistent lung involvement; compounded morbidity with physical weakness, inability to have a normal life
Santiago-Rodriguez et al. (2021)	P1	N/S	Male	Severe	N/S	Complications from lung scarring contributing to use of medications and self-monitoring strategies; impaired airway clearance; physical weakness

Note. N/S = not specified

Theme I: A Novel Health-Illness Transition

Pooled participant data reveal that following recovery from COVID-19, the development of pulmonary fibrosis was an unexpected occurrence and contributed to novel health-illness transitions (Guo et al., 2022; Kurtuncu et al., 2021; Santiago-Rodriguez et al., 2021). The participants explained how they navigated and coped with the complexities of self-management

and treatments such as ongoing oxygen therapy or pulmonary medications (Guo et al., 2022; Kurtuncu et al., 2021; Khoshnood et al., 2021; Santiago-Rodriguez et al., 2021):

*“I’ve got an inhaler here, like, that I keep with me. I keep checking my blood pressure **PI** periodically. I was checking my pulse oximeter all the time. Now I’m down to checking it every other day, every third day...” (Santiago-Rodriguez et al., 2021, p. 11).*

Coping with the pulmonary symptoms and fatigue was a novel experience that required adaptation (Guo et al., 2022; Kurtuncu et al., 2021), often without adequate post-discharge assistance (Guo et al., 2022). This made the transition between health and illness more challenging.

*“I have no one to consult after discharge. I was looking forward to communicating with **H16** doctors. My CT scan results have not been good, and this still concerns me” (Guo et al., 2022, p. 3).*

For some, the lack of post-acute care created feelings of isolation and abandonment during their health-illness transition. This resulted in attempts to improve functional capacity, often without sufficient medical consultation (Guo et al., 2022).

*“I have no medical staff to consult regarding my physical symptoms after discharge. I feel as **H12** if I was abandoned. No one is going to take care of me once I am discharged” (Guo et al., 2022, p. 3).*

H16 *“...I have no alternative but to exercise more” (Guo et al., 2022, p. 3).*

Theme II: Lung Injury and Pulmonary Fibrosis as Antecedent to Illness Uncertainty

Uncertainty about the onset of pulmonary fibrosis or lung damage and its consequences was a major concern for each of the 6 participants (Guo et al., 2022; Kurtuncu et al., 2021; Khoshnood et al., 2021; Santiago-Rodriguez et al., 2021). Concerns about the persistence of the virus in the lungs and reduced pulmonary functioning after a partial recovery led to apprehension and stress related to illness uncertainty (Guo et al., 2021; Khoshnood et al., 2021):

H14 *“I still have a lot of pulmonary fibrosis. Is this fibrosis of the lungs irreversible?” (Guo et al., 2022, p. 4).*

P5 “They say the disease has almost permanent side effects on the lungs and the body becomes weaker and more prone to the disease and the lungs are involved. The idea that I can’t have a normal life after the disease is very stressful for me” (Khoshnood et al., 2021, p. 47).

P1 “Well, now I’ve got a complication with the scar tissue...” (Santiago-Rodriguez et al., 2021, p. 11).

Participants explained how inconsistencies between results of diagnostic tests and subjective experiences of physical symptoms magnified uncertainty (Guo et al., 2022). Newly required adaptation strategies (Kurtuncu et al., 2021), and the unpredictable nature of physical sequelae (Santiago-Rodriguez et al., 2021) were also described as generating an uncertain prognosis.

H12 “I was told that my lungs have recovered after the tests, but I still have a dry cough, chest tightness, and chest pain...” (Guo et al., 2022, p. 3).

P12 “My lungs developed 16-17 lesions from the disease and from the stress. Now I need to cope with this” (Kurtuncu et al., 2021, p. 8).

Theme III: Pulmonary Symptoms Compounded by Fatigue and Weakness

Study participants with pulmonary sequelae commonly experienced cardiopulmonary symptoms, including dyspnea, cough, chest pain, and impaired airway clearance (Guo et al., 2022; Santiago-Rodriguez et al., 2021).

H12 “I also have shortness of breath and require oxygen therapy...” (Guo et al., 2022, p. 3).

These primary effects on the lungs led to fatigue and physical weakness which significantly compounded the symptom experience (Guo et al., 2022; Santiago-Rodriguez et al., 2021).

H12 “I rarely exercised in the past, and I regretted it when I contracted the disease. Thus, now I spend at least one hour a day taking deep breaths or doing aerobics, even if it makes me uncomfortable” (Guo et al., 2022, p. 7).

P1 “But this thing is constantly bugging me because I got mucus that gets trapped that’s hard to cough it out... I’m very tired. I get very fatigued and tired.” (Santiago-Rodriguez et al., 2021, p. 11).

The predominance of pulmonary involvement and the negatively synergistic nature between pulmonary symptoms and physical weakness (Khoshnood et al., 2021) created stress and anxiety

along with significantly impaired pulmonary and functional capacity (Khoshnood et al., 2021; Santiago-Rodriguez et al., 2021):

P1 “...I don’t – I don’t have my normal stamina, you know, going through the day... I’m at – I’m at 50 percent level” (Santiago-Rodriguez et al., 2021, p. 11).

Discussion

This review elucidated the impact of lung injury and pulmonary fibrosis on the experience of long-COVID. Findings show how participants managed symptoms and treatment along an unknown illness trajectory with pulmonary symptoms that were compounded by fatigue and weakness (Guo et al., 2022; Khoshnood et al., 2021; Kurtuncu et al., 2021; Santiago-Rodriguez et al., 2021). These findings can be further explored using three middle-range nursing theories; transitions theory (Meleis, 2015), uncertainty in illness theory (UIT; Mishel, 1988), and the holistic theory of unpleasant symptoms (HTOUS; Moore, 2022), and their implications for clinical nursing practice.

Nursing Care for Transitions with a Novel Illness

The participant data highlighted lung injury as a unique health-related transition that involved high levels of uncertainty and required complex patterns of response. COVID-19 itself is a novel disease and long-COVID is not well understood or classified. The lack of a formal diagnosis, uncertainty and inadequate assistance after discharge made the transition more challenging (Guo et al., 2022; Kurtuncu et al., 2021). Transitional triggers can be influenced by developmental, health-related (acute, chronic), situational, or organizational factors (Meleis, 2015). Understanding the experiences and drivers of the challenges in transition can assist nurses to meet patient care needs.

The International Classification of Diseases does not yet recognize pulmonary sequelae as a subtype of long-COVID (WHO, 2022), making this a vital area for patient advocacy by

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nurses. Medical diagnosis categorizes medical abnormalities by differentiations that are often based on phenotypic (symptoms, physical findings, tests) and biotypic (genetics, biomarkers, inflammatory profiles) criteria (Lockshin et al., 2022). Patients value diagnoses because it provides a meaningful starting point for their health-illness transition period. A formal diagnosis validates patient symptoms, defines illness, and initiates the context for subsequent therapy (Lockshin et al., 2022; Meleis, 2015). Nurses in various clinical positions may encounter patients with a broad diagnosis of "post-COVID condition" (WHO, 2022) with pulmonary sequelae characteristics such as the need for ongoing oxygen therapy, varying CT results, and uncomfortable pulmonary symptoms. Recognizing that a medical diagnosis is a critical juncture along the health-illness continuum, nursing care becomes essential by translating complex science and assisting people to navigate uncertainties with a novel illness such as pulmonary sequelae. Nurses offer a unique perspective to patient's health-illness transition experiences through informed caring of others (Swanson, 1993). A formal diagnosis is a vital beginning point for the health to illness transition. This diagnosis begins the transitions necessary within the health-illness trajectory and creates entry points to the health system. Communication within the interprofessional team to advocate for a formal diagnosis is a meaningful starting point for the patient's health-to-illness transition.

The pandemic has resulted in the failure of several standard care routes and follow-up check points (Bek et al., 2021). Therefore, patients may have difficulty gaining access to health care and receiving a formal diagnosis for their ongoing morbidity, especially in the community. Nurses may encounter patients revealing inadequate post-acute care, such as participants H12 and H16 from the pooled data (Guo et al., 2022). Nurses in various clinical positions can

evaluate the patient's ongoing symptoms and experiences, and their access to healthcare systems.

Antecedent to Illness Uncertainty: Nursing Implications

Lung injury and the development of pulmonary fibrosis were key antecedents to illness uncertainty. The pooled participant data revealed feelings of losing control over illness-related events and that an unknown future can occur at any stage of the illness as sources of uncertainty (Guo et al., 2022; Kurtuncu et al., 2021; Khoshnood et al., 2021; Santiago-Rodriguez et al., 2021). Uncertainty results in poor psychosocial outcomes and lower health-related quality of life, as well as more physical symptoms (Johnson et al., 2006; Parker et al., 2016; Szulczewski et al., 2017). The Uncertainty in Illness Theory (UIT) describes uncertainty as a source of stress for patients (Mishel, 1988) and therefore, understanding the antecedents of uncertainty can guide nursing care. The UIT proposes that the way individuals appraise their uncertainty and build meaning for health-related experiences informs adaptation and new perspectives on life (Mishel, 1988).

Nurses are well positioned to care for patients living with pulmonary sequelae due to their proximity and unique therapeutic relationship with patients. To improve psychosocial outcomes, quality of life, and physical symptoms the nurse can assist patients to navigate gaps in clinical knowledge. By staying abreast of pulmonary sequelae evidence as it develops and performing thorough assessment of the person's appraisal and perception of their illness uncertainty nurses can provide meaningful information (Hansen et al., 2012). Mishel Uncertainty in Illness Scale (MUIS) (Mishel, 1984) is a 34-item scale used to assess uncertainty in symptomatology, diagnosis, treatment, caregiver relationships, and future planning (Wright et al., 2009). The MUIS is factored into four components: (1) ambiguity, (2) complexity, (3) lack of

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information, and (4) unpredictability (Mishel, 1984). Nurses can use the MUIS or its components to assess uncertainty. Following a thorough assessment of illness uncertainty, nurses can co-create an appropriate plan of care for patients with pulmonary sequelae to address the unique concerns of each individual and utilize resources that are available in their local practice settings.

Nursing Care for Pulmonary Symptoms Compound by Fatigue

People with pulmonary sequelae experience a variety of pulmonary symptoms such as chest discomfort, cough, dyspnea, and impaired airway clearance that are frequently exacerbated by the effects of physical weakness and fatigue. Given the synergistic effect of dyspnea and fatigue in pulmonary sequelae, people with long-COVID may need a more holistic approach (Maxwell & Radford, 2021; Wallin et al., 2021). The Holistic Theory of Unpleasant Symptoms (HTOUS; Moore, 2022) describes how multiple symptoms may occur concurrently, interact with one another, and become negatively synergistic. Practice informed by HTOUS includes practice, nursing roles include providing care, coaching with a focus on outcomes, consulting by providing information at the person's explicit request, and advocating by aiding the person in navigating the health care system (Moore, 2022).

Currently, no evidence-informed nursing guidelines are available on symptom management strategies for long-COVID or pulmonary sequelae. However, while knowledge on the clinical trajectory or curability of pulmonary sequelae is limited (Hama Amin et al., 2022) there are promising therapeutic interventions being used. Antifibrotic medications, pulmonary rehabilitation, home oxygen therapy, and lung transplantation (for severe cases) are being repurposed and the efficacy of these treatments are being investigated (Bazdyrev et al., 2021; Bharat et al., 2020). Additionally, some patients are prescribed corticosteroids, anti-fibrotic, anti-

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inflammatory, or immunosuppressive drugs for their pulmonary sequelae (Tanni et al., 2021). Patient's self-report of symptoms is the most trustworthy indicator of symptom severity (Moore, 2022). Therefore, nurses can evaluate the response to these therapies and contribute to growing knowledge base regarding efficacious pulmonary sequelae treatment. The caring and carative nature of nursing practice (Boykin et al., 2021; Watson, 2007) situates nurses to gain insight into patients' perspectives on their long-COVID symptoms to better support them and contribute to evidence-based guidelines. Given the prevalence of dyspnea and fatigue in this group, nurses caring for patients with pulmonary sequelae may utilize conventional measures such as regular dyspnea assessments and tools that evaluate dyspnea and fatigue when evaluating the consequences of unpleasant symptoms (Baker, 2017). Despite the limited clinical knowledge of pulmonary sequelae management, HTOUS-informed practice within the nurse-patient relationship will yield highly personalized assessments of the entire symptom experience and more humanized nursing care practices (Bellier-Teichmann et al., 2021).

The final sample of four studies with six pooled participants is a study limitation due to small sample size. As this is a systematised review of published papers, only published data from participant interviews were used and original data were not accessed.

Conclusion

Understanding the experiences of pulmonary sequelae as a unique subtype of long-COVID can assist nurses to identify and treat individual patient care needs. Recognizing pulmonary sequelae as a novel health-illness transition, lung injury and pulmonary fibrosis as antecedents to illness uncertainty, and that pulmonary symptoms are compounded by fatigue and weakness can guide nursing care strategies. Applying mid-range nursing theories of transitions, uncertainty and unpleasant symptoms can generate understanding and nursing practices that

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support health. While qualitative studies specifically with people diagnosed with pulmonary sequelae are needed, the systemized review contributes knowledge to increase the therapeutic potential of nursing practice. The pooled qualitative findings from a set of related studies and their participants provided valuable insights to guide current nursing practice and inform future qualitative research.

Relevance to Clinical Practice

The challenges of recovering from COVID-19 with pulmonary sequelae symptoms are increased without a formal diagnosis. Nurses can collaborate with the interprofessional team and assist patients to receive and understand diagnosis. A diagnosis can provide a clear starting point in the patient's health-illness transition.

Pulmonary sequelae is an evolving condition that leaves patients with great uncertainty about their health. Disease paths are unknown, and individuals cannot predict their futures. A comprehensive evaluation of a person's perception of ambiguity, disease complexity, information needs, and the unpredictability of their illness will assist in the development of nursing care plans that meet the specific patient's needs. Even while pulmonary sequelae knowledge is growing, nurses must remain current on clinical information and use the powerful caring practices within the therapeutic nurse-patient relationship to provide support and collectively construct meaning to promote well-being in uncertain situations.

Since dyspnea is often accompanied by and/or worsened by fatigue and weakness, nurses should incorporate a holistic assessment using standardized dyspnea and fatigue assessment instruments. This will yield important subjective and objective data to enhance the therapeutic potential of the nurse-patient relationship.

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Chapter 3. Manuscript 2 – A Qualitative Research Protocol for Studying Pulmonary Sequelae of COVID-19

Abstract

The ongoing global impact of the COVID-19 pandemic has underscored the necessity for research on long-COVID, with a particular focus on subtypes. The purpose of this article is to introduce a qualitative study protocol that employs Interpretive Description methodology, rooted in the reciprocal interaction philosophy of science and nursing systems theory to explore the experiences of people with pulmonary sequelae as a subtype of long-COVID. I justify a critical case purposive sampling plan to glean insights from a small yet significant group of participants, guided by inclusion criteria aligned with the Canadian Thoracic Society's indicators of pulmonary sequelae of COVID-19. Also addressed is data collection and analysis methods, reflexivity, rigor, ethical considerations, informed consent, harm mitigation, and participant confidentiality. This study protocol enriches the methodological discourse surrounding long-COVID subtypes and qualitative research, with a specific emphasis on the multifaceted nature of pulmonary sequelae within the context of nursing research.

Background

The global impact of the COVID-19 pandemic has been profound, affecting both public health and societies worldwide. One significant concern arising from this pandemic is the phenomenon known as long-COVID or COVID-19 sequelae, which refers to persistent symptoms experienced by individuals even after their apparent recovery from the acute phase of the illness (Garg et al., 2021; Halpin et al., 2021). In response to this issue, precision health initiatives have emerged with the aim of categorizing long-COVID into various subtypes (Deer et al., 2021; Estiri et al., 2021). Among these subtypes, one characterized by pulmonary sequelae has gained particular attention (Ali & Ghonimy, 2021; Ruggiero et al., 2022; Stewart et al., 2023; Udwardia et al., 2021). Existing literature has emphasized the need for nurses to understand long-COVID subtypes, including those related to pulmonary issues (Albright et al., 2023; Maxwell & Radford, 2021; NHS, 2022). However, qualitative research focused on this specific subtype remains limited, despite its crucial role in generating essential knowledge for nursing practice and complementing advancements in biomedical research and precision healthcare (Myroniuk et al., 2021). To address these gaps, I offer this retrospective account of a qualitative research protocol developed to study the experiences of individuals who have developed pulmonary sequelae following COVID-19 infection. The philosophical assumptions within this protocol contribute to the ongoing methodological discourse of long-COVID and qualitative research.

Methodology

Interpretive Description

For this study, the chosen qualitative research methodology was interpretive description (ID) (Thorne, 2016), given the important responsibilities that nurses have in caring for patients with long-COVID (NHS, 2022). Thorne et al. (1997) developed this methodology specifically

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for nursing research, aligning it with the epistemological foundations of nursing to provide genuine knowledge to be applied to nursing practice (Thorne, 2016). While ID is distinct in its approach, it incorporates elements from various qualitative research methods, such as constant comparative analysis and multiple data collection techniques. ID researchers also acknowledge the multifaceted nature of subjective human experience that aligns with naturalistic inquiry principles (Lincoln & Guba, 1985), which emphasize the intricate, contextual, and subjective nature of reality. As per ID methodology, the research questions for this study were: (1) What are the experiences of adults living with pulmonary sequelae of COVID-19? (2) What are the implications of these findings for healthcare practice, policy development, and further research in this area?

Theoretical Scaffolding

Theoretical scaffolding was employed in this study, which served as the foundational framework to guide the research process while making sense of the data collected and facilitating a deeper understanding of the phenomenon being studied (Thorne, 2016). This framework is not used to test existing theories but rather offers a lens through which researchers can contextualize their data and explore emerging concepts and patterns, leading to nuanced understandings (Chiu et al., 2022; Thorne et al., 2016). In this study, the theoretical scaffolding included the reciprocal interaction philosophy of science (see **Table 1**) and nursing systems theory (Fawcett, 2005; Verberk & Fawcett, 2017). The flexibility and adaptability of this theoretical foundation are particularly relevant, as it allowed for context-specific interpretations.

Onto-Epistemological Assumptions. My ontological stance considered that individuals with pulmonary sequelae manifested specific physiological complications (Reese et al., 2023; Turner et al., 2022). This view aligned with the propositions of the reciprocal interaction

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paradigm, which espouses human wholeness as a composite of physiological, psychological, social, and spiritual dimensions (Fawcett, 2005). It does not pathologize people with pulmonary sequelae but rather temporarily isolates one aspect of human experience (the physiological) for study within the broader context of the whole person, encompassing the psychological, social, and spiritual dimensions. This ontological stance aligns with the core beliefs of ID, which recognizes the multidimensional, context-dependent, and relative nature of reality (Thorne, 2016).

Table 1.

Reciprocal Interaction Philosophy of Science

Reciprocal Interaction

*A synthesis of
organismic, simultaneity,
totality, change,
persistence, and
interactive-integrative
worldviews*

- Human beings are holistic, parts are viewed only in context of the whole.
- Human beings are active, and interactions between human beings and their environments are reciprocal.
- Change is a function of multiple antecedent factors, is probabilistic, and may be continuous or may be only for survival.
- Reality is multidimensional, context dependent, and relative.

Note. Adapted from Fawcett (2005, p. 12-13).

In the structure of nursing knowledge by Fawcett (2005), philosophical perspectives play a crucial role in shaping the discipline's conceptual models and their foundational onto-epistemological assumptions. These conceptual models provide an abstract framework for understanding human beings, health, the environment, and nursing care processes (Fawcett, 2005; Risjord, 2011) by clarifying the paradigmatic neutrality of metaparadigm concepts (Thorne et al., 1997). While no single conceptual model suits all inquiries, certain models are better suited for specific cases (Fawcett, 2017). In my study of individuals with pulmonary sequelae of COVID-19, I acknowledge the evident physiological challenge of lung damage. Extending the

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ontological positions of the reciprocal interaction philosophy, I chose the Neuman Systems Model (NSM) for its epistemological assumptions, recognizing the composite of physiological, psychological, sociocultural, spiritual, and developmental systems that interact and are surrounded by concentric protective layers that respond to stressors (Neuman & Fawcett, 2011). This choice maintains research focus without introducing undue theoretical bias, aligning well with the study aims and methodology.

Methods

Inclusion Criteria

Participants in this study were adults aged 18 and above, of any gender identity or pre-existing comorbidities, who were living with pulmonary complications of COVID-19. They had to understand English and be able to provide informed consent [**Appendix B**]. Participants self-reported indicators of pulmonary sequelae outlined by The Canadian Thoracic Society (Beauchamp et al., 2021) to provide more specificity to the inclusion criteria (see **Table 2**), addressing the epistemological position that there is something to be learned about the experiences of people specifically with pulmonary complications of COVID-19.

Exclusion Criteria

Exclusion criteria for this study included individuals under the age of 18 and those unable to provide informed consent due to cognitive or language barriers. Additionally, I excluded participants who did not report any indicators within the Canadian Thoracic Society's indicators of pulmonary sequelae (Beauchamp et al., 2021). While this exclusion criterion limited the study's scope, it enhanced the recruitment of individuals specifically living with pulmonary complications.

Table 2.

Eligibility Criteria

- New or ongoing respiratory symptoms and functional limitations after resolution of acute COVID-19

AND

New or ongoing requirement for supplemental oxygen after resolution of acute COVID-19

OR

AT LEAST ONE OF:

- Persistent radiographic pulmonary abnormality (i.e., Chest X-ray and/ or CT chest demonstrating new/persistent reticular changes and/or fibrosis after resolution of acute COVID-19)

OR:

- Pulmonary function test results demonstrating new/persistent reduction in lung volumes, airflow limitation, and/or reduction in diffusing capacity after resolution of acute COVID-19
-

Note. Adapted from Beauchamp et al. (2021, p. 10)

Sampling and Sample Size

I employed purposive sampling (Etikan et al., 2016) focusing on individuals with pulmonary sequelae. Critical case purposive sampling, which is particularly beneficial in exploratory qualitative research when a small number of participants can offer significant insights (Etikan et al., 2016; Rai & Thapa, 2015), was suitable for this study. Given the limited prior qualitative exploration of pulmonary sequelae of COVID-19, a small sample size, between 10 and 15 participants, was targeted.

Recruitment

The study utilized a passive recruitment strategy, which involved the distribution of recruitment materials to attract potential participants (Gelinas et al., 2017). Recruitment efforts

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occurred between January 15th and June 15th, 2023. Recruitment materials [**Appendix C**] were distributed through electronic channels, including social media platforms and long-COVID support groups, with the necessary permissions when applicable. Participants initiated contact with the researcher and were provided with the necessary details and documentation [**Appendix D**]. The disclosure of the principal investigator's nursing background in the recruitment materials aimed to make potential participants more comfortable in participating (Thorne, 2016), as they would understand that the research sought to enhance nursing care for individuals with pulmonary sequelae.

Data Collection

Data collection began with the collection of participant characteristics, including age, gender identity, the initial timeframe of COVID-19 infection, indicators of pulmonary complications, and the duration of living with these complications. This information contributed to a rich description of the study participants and contextualized research findings (Connelly, 2013). Data collection techniques consisted of semi-structured interviews conducted via teleconference, telephone, or email responses. This flexibility ensured inclusivity, accommodating individuals who may not have comfortably participated in virtual or telephone interviews due to their symptoms. The semi-structured interview guide (see **Table 3**), which posed questions about the physical, emotional, social, developmental, and spiritual aspects of living with pulmonary sequelae of COVID-19, was developed based on nursing systems theory (Verberk & Fawcett, 2017) [**Appendix E**].

Data Preparation

Interviews were recorded, transcribed manually, and anonymized before data analysis. The principal investigator listened to audio recordings to ensure accuracy, note emotional

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expressions or pauses, and remove identifying information. Participants were assigned pseudonyms (Participant A, Participant B, etc.) to protect their identity. Proofed and anonymized transcriptions were stored securely as source data and were uploaded to NVivo (QRS International, 2015) for data management.

Table 3.

Sample Questions from the Semi-Structured Interview Guide

- Please tell me about your experience of living with long-COVID.
 - Can you tell me about how living with long-COVID has affected you physically?
 - Can you tell me about how you are doing emotionally?
 - Can you tell me about how living with long-COVID has affected your social relationships?
 - Can you tell me about the changes you've had to go through in your life since developing long-COVID?
 - How has living with long-COVID impacted the ways you find meaning in life?
-

Data Management

Computer-Assisted Qualitative Data Analysis Software (CAQDAS), specifically NVivo (QRS International, 2015), was used to support text-based analysis. All recorded and transcribed data were securely stored in a password-protected computer system, with access limited to the research team. The pseudonym naming system connected with the original participant information stored in a separate password-protected folder. Data will be retained for a minimum of five years.

Data Analysis

Data analysis occurred in three phases: sorting and organizing, making sense of patterns, and transforming patterns into findings (Thorne, 2016). The initial step involved reading

transcripts line-by-line to identify in-vivo codes directly from the raw data. These codes were labeled in participants' own words to maintain authenticity (Saldaña, 2021). The second phase entailed grouping codes based on similarities and patterns, fostering the interpretation of relationships among the data. In this phase, 548 in-vivo codes evolved into themes or patterns within the data [**Appendices F & G**]. The themes reflected participants' experiences, offering depth, and meaning to their stories (Saldaña, 2021). The final phase of data analysis moved beyond description to transform patterns into meaningful, interpretive findings (Thorne, 2016) by analytic memo writing and code-weaving (Saldaña, 2021) [**Appendix H**]. The goal was to achieve interpretive authority by ensuring that study findings were closely aligned with the data (Thorne, 2016). The validity and authenticity of the findings were also established through this iterative process.

Rigor and Reflexivity

I maintained study rigor through multiple mechanisms. To ensure that my personal beliefs and values did not unduly influence the findings, I employed reflexivity through journaling. Epistemological integrity was sustained through a justifiable line of reasoning and analytic logic with a documented audit trail [**Appendices F, G, & H**]. Representative credibility, another aspect of rigor, was achieved by capturing the experiences of participants using critical case purposive sampling. Lastly, interpretive authority, which emphasized the importance of the data informing conclusions, was sought throughout the entire research process.

Ethical Considerations

Ethical considerations have been upheld at every juncture of this research. Informed consent, a fundamental ethical principle, was secured from each participant. Participants were informed about the study purpose, procedures, and potential risks [**Appendix B**]. Measures were

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in place to minimize potential harm, such as discomfort, stress, or psychological distress through the development of a distress protocol (Dempsey et al., 2016) [**Appendix I**], and to protect the participants' confidentiality and privacy. This research was approved by an institutional Research Ethics Board (Ethics File No: 25083) [**Appendix J**].

Conclusion

Qualitative research of long-COVID subtypes is lacking and no methodological guides are available yet in this domain. I offer this study protocol as an introductory foundation and a practical illustration for focused qualitative research that addresses the needs of nursing care in the context of long-COVID subtypes. Through the utilization of ID methodology and a theoretical scaffolding rooted in the reciprocal interaction and nursing systems theory, a deep understanding of the complex nature of pulmonary sequelae of long-COVID was gained without being bound by inflexible theoretical constraints. Using a purposive sampling strategy, particularly critical case purposive sampling, allowed researchers to capture the experiences of a small yet significant group of participants with pulmonary sequelae of COVID-19. The underlying philosophical assumptions inherent within this protocol contributed to ongoing methodological discourse and can be used to inform future research.

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**Chapter 4. Manuscript 3 – Pulmonary Sequelae of COVID-19: A Qualitative Interpretive
Description Study**

Abstract

Background: COVID-19 sequelae, often referred to as long-COVID, has been divided into subtypes based on organ dysfunction. Persistent pulmonary symptoms and organ dysfunction is a common subtype and therefore understanding peoples' experiences is important for effective healthcare. Understanding can inform the development of precision health strategies when combined with biomedical research. Given the current lack of qualitative research in this area, this study was conducted to describe the experiences and healthcare needs of adults with pulmonary sequelae of COVID-19 to contribute to pandemic recovery efforts.

Method: Semi-structured interviews with 10 participants were recorded, transcribed, and analyzed iteratively using Interpretive Description methodology to generate knowledge for practice.

Results: 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.

Conclusion: Understanding burdens associated with the pulmonary subtype of long-COVID such as respiratory symptoms, fatigue, activity intolerance, emotional upset, and inaccessible healthcare can lead to the development and implementation of strategies that support recovery. Further research is needed to evaluate the impact of clinical strategies on health outcomes.

Introduction

Long-COVID involves symptoms and/or organ dysfunction lasting beyond the expected recovery period (Garg et al., 2021; Halpin et al., 2020). Early in the pandemic, post-mortem data highlighted the severe impact that COVID-19 had on the lungs (Suran, 2021). Many individuals who survived COVID-19, even those with relatively mild cases, exhibited residual pulmonary complications (George et al., 2020; Hama Amin et al., 2022; Ruggiero et al., 2022; Scelfo et al., 2020). 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 (Myroniuk et al., 2021). Identifying patient experiences with various clinical subtypes of long-COVID can aid in the development of precision healthcare (Deer et al., 2021; Estiri et al., 2021). 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 and Purpose

Studies reveal that over half of people hospitalized with COVID-19 exhibited lung abnormalities at three months, six months, and one-year post infection (Huang et al., 2021; Luger et al., 2022; Shah et al., 2020; Zhao et al., 2020). Common respiratory symptoms include dyspnoea, cough, and chest pain (Centers for Disease Control and Prevention, 2023). Infection with SARS-CoV-2 is thought to trigger ongoing damage-repair processes affecting airway remodeling or fibrosis (Al-Jahdhami et al., 2022; Esendağlı et al., 202). Deficits in diffusion capacity affect 20-30% of people who had mild to moderate COVID-19, and 60% of those with severe cases (Thomas et al., 2021). Turner et al. (2023) classified such complications as non-

syndromic long-COVID, marked by organ dysfunction, in contrast to syndromic long-COVID, where no underlying pathophysiological process is identified. 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 (Harris, 2023).

Understanding the human experiences with different clinical subtypes of long-COVID is important for the development of precision health strategies (Turner et al., 2023). A systematised 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 (Albright et al., 2023). 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?

Methods

Study Design

This study employed Interpretive Description (ID), a qualitative research methodology used to inform nursing and applied practice (Thorne, 2016). 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. Email responses were used to accommodate participants dealing with dyspnoea and fatigue. To explore individual's

experiences with this subtype of long-COVID, a reciprocal-interaction philosophy of science (Fawcett, 2005) and interview questions (**Table 1**) adapted from nursing system's theory (Verberk & Fawcett, 2017) were used to achieve theoretical scaffolding (Thorne, 2016).

Table 1.

Sample Questions from the Semi-Structured Interview Guide

- Please tell me about your experience of living with long-COVID.
 - Can you tell me about how living with long-COVID has affected you physically?
 - Can you tell me about how you are doing emotionally?
 - Can you tell me about how living with long-COVID has affected your social relationships?
 - Can you tell me about the changes you've had to go through in your life since developing long-COVID?
 - How has living with long-COVID impacted the ways you find meaning in life?
-

Recruitment

Using critical purposive sampling (Etikan, 2016), participants were recruited from long-COVID support groups on social media. Eligibility criteria included age 18 or above, able to understand English, provide informed consent, and meet the subjective reporting of indicators of pulmonary sequelae outlined by Beauchamp et al. (2021) (**Table 2**). 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).

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 line-by-line while listening to

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the transcript ensured accurate transcription and was the first step in sorting and organizing the raw data. Using coding procedures in NVivo 11 (QRS International, 2015), 548 in-vivo codes were identified in the first coding cycle. 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 (Thorne et al., 2004). 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 (Thorne, 2016). In the final phase of coding and analysis, three main findings were identified through an iterative process of analytic memo writing and code-weaving (Saldaña, 2021) and while considering knowledge that was not previously known (Thorne, 2016).

Table 2.

Eligibility Criteria

- New or ongoing respiratory symptoms and functional limitations after resolution of acute COVID-19

AND

New or ongoing requirement for supplemental oxygen after resolution of acute COVID-19

OR

AT LEAST ONE OF:

- Persistent radiographic pulmonary abnormality (i.e., Chest X-ray and/ or CT chest demonstrating new/persistent reticular changes and/or fibrosis after resolution of acute COVID-19)

OR:

- Pulmonary function test results demonstrating new/persistent reduction in lung volumes, airflow limitation, and/or reduction in diffusing capacity after resolution of acute COVID-19

Note. Adapted from Beauchamp et al. (2021, p. 10)

Results

In total, ten (n=10) participants (**Table 3**) joined this study by either teleconference (n=4), telephone (n=2), and email (n=4). 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 previously used to assess inclusion criteria (Albright et al., 2023; Beauchamp et al., 2021), four participants reported sequelae consistent with obstructive complications, three with restrictive complications, two with embolic complications, and one with non-specific reductions in lung functioning. 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) (**Table 3**).

Findings

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 3.

Participant Characteristics

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

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

Finding 1 – The Illness Burden of Pulmonary Dysfunction & 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:

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***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.*

Dyspnoea 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, 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.*

Hypoxia was a common experience among participants following hospitalization, necessitating ongoing oxygen therapy. 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 pulmonary function testing (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.

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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 paraesthesia 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) often grappled more with the consequences of persistent coughing, and those who had experienced intensive care treatment had additional burdens of the lasting effects from these interventions.

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.

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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

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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

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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.

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 that long-COVID was primarily a psychosomatic influenced 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.*

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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:

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***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:

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***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.

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

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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 (Albright et al., 2023; Hossain et al., 2023) underscoring the significance of these symptoms. This alignment validates the persistent fatigue, dyspnoea 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. (2021) recommend that clinicians maintain a heightened level of clinical suspicion for pulmonary complications of COVID-19. 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. (2023) underscored the impact of COVID-related lung damage on the uncertainty associated with the illness. Our study expands on this, shedding light on how physical complications and symptoms contributed to the emotional turmoil experienced by participants with this long-COVID subtype. The assessment and management of uncertainty is a crucial aspect of nursing knowledge (Mishel, 1990). Participants

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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 to engage in meaningful patient supports. Future research should concentrate on refining the understanding of the distinctive challenges faced by individuals with pulmonary complications and evaluating healthcare strategies aimed at addressing their specific needs.

Albright et al. (2023) documented how a diagnosis of pulmonary sequelae could validate the condition and facilitate access to care along the health-illness continuum. 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 (Byrne, 2022; Gorna et al., 2021). This study underscores the adverse consequences of downplaying physical repercussions of long-COVID on participants with pulmonary sequelae. 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 (Carel & Kidd, 2014). 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

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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 (Burton et al., 2022; O'Brien et al., 2023). 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. (2023) urges greater awareness of organ dysfunction in the general population. 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. 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 (Besnier et al., 2022; Chen et al., 2022; Nopp et al., 2022; Zampogna et al., 2021), and this study illustrates the importance of introducing these programs

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into care pathways. 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.

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.

Conclusion

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 sequelae and to measure the impact of new healthcare strategies on patient health outcomes.

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Chapter 5. Conclusion

This thesis, composed of three manuscripts, was crafted in response to the imperative for nurses to gain understanding of various subtypes of long-COVID, specifically pulmonary sequelae. A qualitative systematised review brought to light important insights for clinical nursing practice. However, it also underscored the noticeable gap in our understanding of the patient experiences related to pulmonary sequelae as a specific subtype of long-COVID. This deficiency was particularly problematic as qualitative research plays a pivotal role in shaping the knowledge base required by nurses for their critical thinking abilities in clinical practice.

To address these concerns, a qualitative study was designed that introduced innovative approaches to the philosophical and methodological aspects of qualitative research within the context of long-COVID. These innovations were aimed at providing more targeted and precise alignment with pulmonary sequelae of COVID-19, a facet that is currently underrepresented in the existing literature. The prevailing research encompassed long-COVID in a general sense. While this body of work is undoubtedly significant, the current landscape necessitated a more focused and precise understanding of patient experiences, especially considering the evolving recognition of long-COVID subtypes associated with specific body system dysfunctions.

Ultimately, original qualitative research was conducted, revealing vital insights into participant experiences, encompassing symptomatology, emotional responses to lung injury, and barriers to accessing healthcare. The knowledge derived from this study has the potential to enrich various domains of nursing practice, policy development, and methodological discourse for further research.

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Appendix A: JBI Critical Appraisal Checklist for Qualitative Research

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer ___ Cameron Albright **Date** 01/06/2022

Author Guo et al. **Year** 2021 **Record Number** 4

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology? <u>Lived experiences = phenomenology</u>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives? <u>What are the post-discharge experiences and needs of COVID-19 survivors?</u>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data? <u>Interviews using semi-structured interviews</u>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data? <u>All participant meanings were represented throughout the study's findings and discussion</u>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results? <u>Two authors were involved with analysis and an example of the coding process was provided</u>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically? <u>The authors describe that they are using phenomenology, however, a distinction of descriptive vs. interpretive phenomenology is not provided</u>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed? <u>Yes, the authors outline their steps to enhance credibility, transferability, dependability, and confirmability</u>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PULMONARY SEQUELAE OF COVID-19

8. Are participants, and their voices, adequately represented?
 Direct quotations from each participant are represented in some capacity throughout the entire study's findings and discussion.
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
 The study was approved by the Xi'an Jiaotong University Health Science Center (Ref: 2020-1331)
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
 Yes, the conclusions and themes are congruent with the findings described through participant quotes and interpretation
- Overall appraisal: Include Exclude Seek further info

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer Cameron Albright Date 01/06/2022

Author Kurtuncu, Kurt, & Arslan Year 2021 Record Number 7

- | | Yes | No | Unclear | Not applicable |
|---|-------------------------------------|--------------------------|-------------------------------------|--------------------------|
| 11. Is there congruity between the stated philosophical perspective and the research methodology?
The authors used phenomenology and Collaizzi's method of analysis, but no stated philosophical perspectives are noted. | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| 12. Is there congruity between the research methodology and the research question or objectives?
Yes, phenomenology = lived experiences | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| 13. Is there congruity between the research methodology and the methods used to collect data?
Interviews using semi-structured interviews | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 14. Is there congruity between the research methodology and the representation and analysis of data? | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

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Data was represented in accordance with COREQ and analyzed using Colaizzi’s phenomenological method

- 15. Is there congruity between the research methodology and the interpretation of results?
Two authors were involved with analysis and themes and subthemes were generated using Colaizzi’s analysis method
- 16. Is there a statement locating the researcher culturally or theoretically?
Phenomenology is used, but there is no statement found to locate the researchers culturally or theoretically
- 17. Is the influence of the researcher on the research, and vice-versa, addressed?
Yes, the authors outline their steps to enhance reflexivity and trustworthiness of their results
- 18. Are participants, and their voices, adequately represented?
Direct quotations from each participant are represented in some capacity throughout the entire study’s findings and discussion.
- 19. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
The study was approved by ethics committee (No. 2020/20)
- 20. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
Yes, the conclusions and themes are congruent with the findings described through participant quotes and interpretation

Overall appraisal: Include Exclude Seek further info

JBIC Critical Appraisal Checklist for Qualitative Research

Reviewer ___ Cameron Albright Date 01/06/2022

Author ___ Khoshnood et al. Year 2021 Record Number 8

PULMONARY SEQUELAE OF COVID-19

	Yes	No	Unclear	Not applicable
21. Is there congruity between the stated philosophical perspective and the research methodology? <i>No philosophical perspective is mentioned but the authors explain that they are using conventional content analysis</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
22. Is there congruity between the research methodology and the research question or objectives? <i>The study sought to explore patient experiences of living with COVID-19, but no qualitative research methodology (i.e., phenomenology or narrative) is mentioned.</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
23. Is there congruity between the research methodology and the methods used to collect data? <i>Interviews using semi-structured interviews is an acceptable approach to qualitative inquiry</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. Is there congruity between the research methodology and the representation and analysis of data? <i>Conventional content analysis was used for data analysis and represented as themes; but the congruency is unclear due to lack of clear qualitative methodology</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
25. Is there congruity between the research methodology and the interpretation of results? <i>Conventional content analysis was used for data analysis and represented as themes; but the congruency is unclear due to lack of clear qualitative methodology</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
26. Is there a statement locating the researcher culturally or theoretically? <i>There is no statement of cultural or theoretical orientation other than the use of qualitative methods</i>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. Is the influence of the researcher on the research, and vice-versa, addressed? <i>Yes, the authors outline their steps to enhance credibility, transferability, dependability, and confirmability</i>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PULMONARY SEQUELAE OF COVID-19

28. Are participants, and their voices, adequately represented?
 Direct quotations from participants are represented in some capacity throughout the entire study's findings and discussion.
29. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
 The study was approved by Ethics Committee of the Vice Chancellor for Research and Technology of Kerman University of Medical Sciences
30. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?
 Yes, the conclusions and themes are congruent with the findings described through participant quotes and interpretation
- Overall appraisal: Include Exclude Seek further info

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer Cameron Albright Date 01/06/2022

Author Santiago-Rodriguez et al. Year 2021 Record Number 10

- | | Yes | No | Unclear | Not applicable |
|--|-------------------------------------|--------------------------|-------------------------------------|--------------------------|
| 31. Is there congruity between the stated philosophical perspective and the research methodology?
No philosophical perspective is mentioned but the authors explain that they are using thematic analysis for data analysis | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| 32. Is there congruity between the research methodology and the research question or objectives?
The study sought to explore the illness experience of those with COVID-19 but no qualitative research methodology (i.e., phenomenology or narrative) is mentioned. | <input type="checkbox"/> | <input type="checkbox"/> | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| 33. Is there congruity between the research methodology and the methods used to collect data? | <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

PULMONARY SEQUELAE OF COVID-19

- Interviews using semi-structured interviews is an acceptable approach to qualitative inquiry
34. Is there congruity between the research methodology and the representation and analysis of data?
 Thematic analysis was used for data analysis and represented as themes; but the congruency is unclear due to lack of clear qualitative methodology description
35. Is there congruity between the research methodology and the interpretation of results?
 Thematic analysis was used for data analysis and represented as themes; but the congruency is unclear due to lack of clear qualitative methodology
36. Is there a statement locating the researcher culturally or theoretically?
 There is no statement of cultural or theoretical orientation other than the use of qualitative methods (thematic analysis of interviews)
37. Is the influence of the researcher on the research, and vice- versa, addressed?
 The authors clearly outline their procedures and analysis plan, but it remains unclear the recognition of the influence the researcher, and vice-versa, had on the study outcomes.
38. Are participants, and their voices, adequately represented?
 Direct quotations from participants are represented in some capacity throughout the entire study's findings and discussion.
39. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
 The study was approved by the University's Committee on Human Research
40. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

PULMONARY SEQUELAE OF COVID-19

Yes, the conclusions and themes are congruent with the findings described through participant quotes and interpretation

Overall appraisal: **Include** Exclude Seek further info

Appendix B: Consent Form

Principal Investigator (Researcher):

Cameron Albright BScN, RN, CMSN(C)
calbright1@learn.athabascau.ca

Supervisors:

Dr. Jacqueline Limoges Ph.D., RN
Dr. Gwen R. Rempel Ph.D., RN

Study Title: Helping Nurses Understand What It Is Like to Live with Lung Complications of Long-COVID.

What is the purpose of this research?

The purpose of this research is to understand the experiences of people living with long-COVID who have ongoing lung complications. Your involvement will help nurses understand what it is like to live with long-COVID which could help them better provide care.

What am I being asked to do?

You are invited to participate in a one-hour virtual, telephone, or text-based interview with Cameron Albright, the principal investigator. During the interview, you will be asked questions about how long-COVID is affecting your life overall and the experiences you have with it. You will also be asked general questions about yourself such as age, gender, your initial COVID infection, and how long you've been living with long-COVID. With your permission, virtual interviews will be audio-recorded using Microsoft Teams, and telephone interviews will be recorded on the researcher's computer. Text-based interviews will be on Microsoft Teams using the 'chat' feature or by email.

Option A. Virtual interview using Microsoft Teams.

Option B. Telephone interview

Option C. Text-based interview using Microsoft Teams.

Option D. Text-based interview by email to complete on your own time.

Taking part in this study is your choice.

You can choose to take part in this study or not take part in this study. It is voluntary. You can also change your mind any time and withdraw from this study or choose not to answer any questions. Whatever choice you make, there will be no consequences to you. If you wish to withdraw from this study, contact Cameron at calbright1@learn.athabascau.ca. Withdrawal of your interview responses is possible until identifying information is removed (anonymized). Your responses will be anonymized **one-week (7 days)** after your interview, therefore it will not be possible to withdraw your responses after this point.

This document has important information to help you make your choice. Take time to read it. It is important that you have as much information as you need and that all your questions are answered. See the "where can I get more information" section if you have more questions.

Who is conducting the research?

This research is being conducted by Cameron Albright BScN, RN, CMSN(C), a Master of Nursing student at Athabasca University. This research is supervised by Dr. Jacqueline Limoges Ph.D., RN and Dr. Gwen R. Rempel Ph.D., RN.

How are my rights as a research participant protected?

Information gathered during the study will be held confidentially by the researchers and any reporting on the data will be done in such a way that you will not be identified. The study results may be used in presentations and publications. Data will be reported in a general way and you will not be identified in any way.

Only Cameron Albright and his thesis supervisors will see the data.

The research team involved in this study is committed to protecting your privacy and has multiple safeguards in place to do so. However, while every precaution has been taken to protect your private and confidential information, the risk of loss or misuse of the information cannot be completely eliminated. In the unlikely event that this occurs, you will be notified at the first reasonable opportunity.

Are there risks or benefits to participation?

Discussing your personal experiences of COVID-19 may be upsetting. You may choose to end the interview and continue the interview at a later date or end the interview completely at any time. If you feel upset and need additional mental health support, you can access resources by calling **1-866-585-0445** or text WELLNESS to 741741.

If you are distressed and/or in crisis, you may also call the crisis helpline toll-free at **1.833.456.4566**. **If it's an emergency, please call 911.**

Is there compensation or cost to participate?

To show our appreciation for your time taken to participate in this study, you will be compensated with a \$35.00 CAD Amazon e-gift card. Even if you cannot complete the whole interview or chose to withdraw your responses, you will still receive the e-gift card. There is no cost to you to participate in this study.

Where can I get more information?

This study is approved by the Athabasca University Research Ethics Board (REB). If you have any questions regarding your rights as a participant in this study, please contact the REB at rebsec@athabascau.ca or 780.213.2033.

If you have any questions about this study, want additional information, or wish to withdraw your participation please contact Cameron Albright at calbright1@learn.athabascau.ca

Conflict of Interest

The researchers have no conflict of interest to declare.

Next Steps

If you consent to participating in this study, please join the interview of your choice with Cameron Albright at the mutually agreed upon date and time. You will be asked once more to provide verbal consent before the interview and any audio recording starts.

Appendix C: Recruitment Poster

VOLUNTEERS NEEDED FOR A STUDY ABOUT LONG-COVID

Do you:

- have lung damage/injury or changes on medical tests (like an x-ray, CT scan, pulmonary function tests) after COVID-19?

Or do you:

- need ongoing oxygen therapy after COVID-19 and experience breathing problems?

If so, please consider participating in the study by emailing:

Cameron Albright, RN at : calbright1@learn.athabasca.ca to set up a one-hour virtual, telephone, text-based, or email interview to answer questions about you and your experience with long-COVID.

To show our appreciation for your time, you will receive a \$35.00 CAD Amazon e-gift card for participating in this study.

I am a registered nurse (RN) studying the experiences of adults (above age 18) living with long-COVID who have ongoing lung complications. Your involvement will help nurses better understand what it is like to live with long-COVID.

This study is supervised by Dr. Jacqueline Limoges Ph.D., RN and Dr. Gwen Rempel Ph.D., RN and has been approved by Athabasca University's Research Ethics Board.



Appendix D: Email Response Script for Potential Participants

Dear _____,

Thank you for your email and interest in this study!

The next step is to set up a mutually convenient time to talk for about 60 minutes by virtual, telephone, or text-based interviewing. Are you available on any of these days/times? (**Give a few options below**). You may also choose to answer interview questions by email on your own time.

It is possible that discussing your experiences with COVID-19 may be upsetting. You may choose to end the interview at any time. This is a confidential study and nothing you say will be linked back to you.

Your participation in this study is completely voluntary and you can change your mind and withdraw anytime without any risks. The data from your interview can be deleted up to one week after the end of the interview if requested.

To show our appreciation for your time taken to participate in this study, you will be compensated with a \$35.00 CAD Amazon e-gift card. Even if you cannot complete the whole interview or chose to withdraw your responses, you will still receive the e-gift card.

Researcher Information: The study is being conducted by Cameron Albright, a Master of Nursing student at Athabasca University. The study is supervised by Dr. Jacqueline Limoges and Dr. Gwen Rempel.

If you have any questions regarding your rights as a participant in this study, please contact the REB at rebsec@athabascau.ca or 1-780.213.2033.

The consent form for this study is attached to this email. Please review it before making your decision and let me know if you have any further questions and your preferred method of interview:

Option A. Virtual interview using Microsoft Teams.

Option B. Telephone interview

Option C. Text-based interview using Microsoft Teams.

Option D. Text-based interview by email to complete on your own time.

Sincerely,

Cameron Albright

Appendix E: Semi-Structured Interview Guide

Opening Questions

CAN I START THE RECORDING?

- Before moving into the questions about your experiences with COVID-19, I want to get to know you a little and ensure that I properly address you.
- Can you tell me your pronouns (example, he/her/they) and gender, and the name I should call you?
- What is your age?
- When were you first infected with COVID-19? Were you hospitalized?
- How long have you been living with long-COVID?
- Do you require ongoing oxygen therapy and experience trouble breathing, coughing, or difficulty completing everyday activities since having COVID-19?
- Has your doctor, nurse practitioner, or specialist told you that you have ‘lung damage’, ‘lung injury’, or ‘pulmonary fibrosis’ or changes on medical tests (like an x-ray, CT scan, pulmonary function tests) since having COVID-19?

Interview Questions

** = *probing questions*

1. Please tell me about your experience of living with long-COVID.
2. Can you tell me about how living with long-COVID has affected you physically?
 - ** *When I say “unpleasant symptoms” what comes to your mind?*
 - ** *What is it like to live with “unpleasant symptoms”?*
3. Can you tell me about how you are doing emotionally?
 - ** *What comes to mind when I say the word “uncertainty”?*
4. Can you tell me about how living with long-COVID has affected your social relationships (i.e., family, friends, colleagues)?
5. Can you tell me about the changes you’ve had to go through in your life since developing long-COVID?
 - ** *What comes to your mind when I say “milestones” or “goals”?*
6. How has living with long-COVID impacted the ways you find meaning in life?

PULMONARY SEQUELAE OF COVID-19

7. What would you want a nurse to know about you if they were taking care of you right now?
8. Thinking back on the nursing care you have received to help you live with long-COVID, how could that care be improved?
9. Is there anything else you want to tell me today?
10. How was this interview/questionnaire for you?

Appendix F: Initial Analysis Chart and In-Vivo Coding

PARTICIPANT/ INTERVIEW TYPE	AGE	INITIAL COVID INFECTION	PATIENT REPORTED OUTCOMES (PROs) OF PULMONARY SEQUELAE
A Option A [Virtual]	40- 49	May 2022	<i>“So, then my doctor sent me for a chest X-ray, and it showed that I had hyperinflation of the lungs.”</i>
B Option B [Telephone]	30- 39	Feb. 2022	<i>“Then they diagnosed me with, with blood clots in my lungs, like micro clots, and about two weeks before that I had gone to the hospital initially and had pneumonia in my lung and fluid. So, I, I think both of those were two issues that I was dealing with, with the same time.”</i>
C Option D [Email]	60- 69	Nov. 2021	<i>“C.T Scans of my lungs post-COVID revealed pulmonary fibrosis in all lobes of the lungs. A respirologist stated I would live with these scar tissues the remaining of my life. He added that it ‘could go 2 ways: stabilise, or progress’ into complications that would require other treatments besides using the 3 Rx of inhalers I was prescribed at the time. In October 2022, [...] I saw another respirologist who reported that the results of a second C.T. scan in September 2022 revealed the lungs were now clear, free of any fibrosis, and that I could stop all Rx inhalers.”</i>
D Option A [Virtual]	60- 69	Sept. 2021	<i>“So initially I had CTs, and they found the COVID, COVID pneumonia on both lungs. I had triple pneumonia and embolisms, pulmonary embolisms, so that's why they sent me out. I've had CT done approximately 6-7 months ago and they saw improvement, but there was still scarring and damage. I've had an echo. I don't know if that was for heart or if that was for, for lungs. I remember the, the, the technician said ‘boy, you've smoked a long time’ and I was like, I don't smoke, you know. So yeah, I haven't had one for a while, we'll see what this next appointment does, if I have another. They are seeing improvement, but it's, it's very slow.”</i>
E Option A [Virtual]	40- 49	Dec. 2022	<i>“...was found to have a pulmonary nodule on x-ray and then multiple nodules, mucus plugging, and bronchiectasis on CT, with an overlying pseudomonas infection. I have a history of asthma, but the lung findings are new. [...] I found in my cultures from when I talked to you that I have MAC. It was picked up due to the bronchiectasis from the COVID infection. I'm meeting with Infectious Disease within the week to</i>

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			<i>see if I need to begin treatment soon. Treatment is 12-18 months of three antibiotics.</i>
F Option D [Email]	40-49	Feb. 2020	<i>"I have difficulty breathing and a bad cough. I have difficulty completing everyday activities... symptoms are worse in the evenings. The cough impacts my sleep. My oxygen levels continue to decrease. It's worrying to me. I have been sent for spirometry testing. Tests are inconclusive. I have been diagnosed with asthma. I take Symbicort 200 4x daily."</i>
G Option D [Email]	40-49	Sept. 2022	<i>"CPAP, recently diagnosed with heart issues, and COPD. No O2, but pressure on chest, struggle to breathe, winded easily, coughing continues all day, fatigue, significant reduction in exercise and activity. Yes, have had x-ray, CT scan, or pulmonary function tests which resulted in COPD diagnosis. I am a lifetime non-smoker, no asthma, no issues until now."</i>
H Option B [Telephone]	50-59	Dec. 2021	<i>"So, the lung specialist thought I had an embolism [...], a clot in my lung. So, she sent me for, [...] scintigraphy, a, it's kind of scan I guess... scintigraphy VQ, and the CT-HR graphic that, [...], that's another test. And she did a spirometry, a CT of the chest and a scan perfusion blood test. So, everything was good... except for the, for the... pulmonary function test was down to 67"</i>
I Option D [Email]	60-69	Sept. 2021	<i>"Blood clots in lungs. Angiogram, CT, MRI and pulmonary function tests to ensure not extending to heart. Ongoing."</i>
J Option A [Virtual]	40-47	Oct. 2021	<i>"I went for an X-ray. And I guess they saw some scarring. What they thought for, from an X-ray, so they weren't quite happy with that. So, they sent me for a CT scan, so I went for a CT scan at the hospital, and that would have been in July of 2022 and that's when they saw definite it was pulmonary fibrosis. So, I have some scarring due to, well, everything COVID, and I've been sent to a respiratory specialist [...]. So, they're thinking that, obviously I know I've been told that, like, 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 sort of thing so that's, that's where I'm at right now."</i>

**PARTICIPANT [A] 1st CYCLE IN-VIVO
CODES**

15-20 POUNDS
A LOT MORE APPOINTMENTS
ALWAYS HAVE MY VENTOLIN
APPOINTMENT TIMES
BREATHING TEST REALLY DIFFICULT
CAN'T DO THAT ANYMORE
DEPENDS ON THE ACTIVITY
DIDN'T REALIZE HOW MUCH THE
VENTOLIN HELPS
ENJOYING MY READING AND YOGA
EXERT MYSELF
FRUSTRATED WITH ME
GOOD DAYS AND BAD DAYS
HANDLING THIS OK ON MY OWN
HOPEFULLY MORE TIME IS ALL
I DO MISS MY RUNNING
I DON'T HAVE ANY OF THAT [BRAIN
FOG]
I DON'T THINK I NEED THAT MUCH
SLEEP
I HAVE TAKEN UP YOGA
I WAS VERY ACTIVE
I'M A FAIRLY INDEPENDENT PERSON
I'M A POSITIVE PERSON
I'M ALSO HOPEFUL
I'M DOING GOOD

INHALERS HELPED ME ALOT
LITTLE BIT BETTER
LONG WAIT UP TO SIX MONTHS
LONG WAITING FOR APPOINTMENTS
LUNGS ARE ALREADY BAD
MORE EXERTION THAN USUAL
NAP FOR 3 OR 4 HOURS
NERVOUS TO GET IT AGAIN
NO ONE HAS ANY ANSWERS
NO ONE KNOWS
NO ONE REALLY KNOWS
PARANOID AT FIRST
PEAK FLOW METER
POSITIVE SPIN ON IT
SHORTNESS OF BREATH RIGHT
AWAY
SICK FOR A FEW DAYS AFTER
[BREATHING TEST]
THREE MONTHS LATER
TWO INHALERS THAT I USE NOW
WALK AT A SLOW PACE
WASH MY HANDS AL THE TIME
WOULDN'T BE ABLE TO DO IT
WITHOUT MY INHALERS
WOULDN'T BE EXERTING MYSELF

**PARTICIPANT [B] 1st CYCLE IN-VIVO
CODES**

A LOT MORE CAREFUL THAN I HAVE
IN THE PAST
ANEMIC NOW [BLOOD THINNERS]
BE A NURSE FOR THE RIGHT
REASONS
BLOOD CLOTS IN MY LUNGS
BLOOD THINNERS
BRAIN FOG
BREATHING PROBLEMS SINCE
BUDESONIDE
CARE AND COMPASSION
COMPLETELY KNOCKED OUT
CONSIDER MYSELF VERY LUCKY
DE-ESCALATION
DEEP PAIN [LUNGS]

DETAILS AND INTRICACIES I FEEL IS
VERY IMPORTANT
DIFFICULT BUT STILL MANAGEABLE
DIFFICULT TO DO THE DEEP
BREATHS
DOESN'T MAKE ME AFRAID OF
DEATH
DONT HAVE SOMEBODY [...] ABLE TO
FOLLOW UP ON THE LITTLE THINGS
EASIER HOBBIES
FAMILY
HATE DOING YOGA
HAVEN'T SEEN THE RESULTS
HAVENT BEEN ABLE TO TRAVEL
HAVING TROUBLE SLEEPING

PULMONARY SEQUELAE OF COVID-19

HELPED WITH THE OPENING UP MY LUNGS
HEMATOLOGIST
HURT MY LUNGS TOO MUCH
HYPERINFLATION OF THE LUNGS
I DO GET TO CONTINUE TO LIVE
I DO HAVE A PUFFER
I DONT HAVE A FAMILY DOCTOR
I'VE BEEN LET GO [EMPLOYER]
IN THE TRASH [BREATHING]
INTEGRATED POST COVID
NAVIGATIONAL TEAM
INTERSECTIONALITY
IRON TREATMENT
IT'S JUST SO EXHAUSTING
ITS A NEW SCARY WORLD
LEFT-LEANING
LISTEN AND UNDERSTAND
LUNG CAPACITY
MONTHLY IRON TRANSFUSION
MORE ACTIVITY THAN USUAL
MY DIAPHRAGM HURTS
NOT QUITE AS BAD AS IT WAS
NOT REALLY ROOM FOR PEOPLE IN
GENERAL WITH DISABILITIES
ON TOP OF SOMETHING I WAS ABLE
TO COPE WITH

PARTICIPANT [C] 1st CYCLE IN-VIVO CODES

1 YEAR AND 4 MONTHS
ACTIVITIES I AM NO LONGER ABLE
TO TAKE PART IN AFFECTS MY
COGNITIVE ABILITIES
ANXIETY OVER DYSPHAGIA
AVOID PHONE CALLS OR BEING
WITH PEOPLE AWKWARD AND
EMBARRASSING SITUATION
CAN'T FOCUS ... TRIGGERS ANXIETY
AND PANIC
CARDIAC ARREST TRIGGERED BY
COVID
COGNITIVE IMPAIREMENTS [...]
SENSE OF FAILURE AND DEFEAT
DEEPEST STRUGGLE IS NOT HAVING
THE ENERGY

OTHER PEOPLE THAT ARE IN
SIMILAR SITUATIONS
PNEUMONIA IN MY LUNG AND FLUID
REALLY HARD TIME
SEVERE PAIN IN MY LUNGS
SHE KNOWS WHAT SHES DOING AND
IM SAFE HERE
SOMEBODY ACTUALLY LISTENED
[POST COVID NAVIGATION TEAM]
STOP BEING A VICTIM
SYSTEM THAT YOU KIND OF HAVE
TO GO THROUGH
TEND TO FORGET IT [PUFFER]
THEY ARE VERY PAINFUL [YOGA
BREATHING]
THINGS TOPPLE OVER ALL AT ONCE
TWICE AS LONG AS IT WOULD IN THE
PAST
VALIDATED IT
VERY DIFFICULT TIME ACTUALLY
DOING THE BREATHNIG TEST
VERY GRATEFUL FOR WHAT I HAVE
VERY LONELY ROAD
VETERANS AFFAIRS [PTSD]
WHY CAN'T I DO THIS

DEGREE OF UNDERSTANDING
DID NOT REFER ME TO A
RESPIROLOGIST
DID NOT SOUND LIKE MY VOICE AT
ALL DIFFICULTIES EXPRESSING A
THOUGHT
DOCTORS SUPPORT WOULD HAVE
BEEN A TREMENDOUS HELP
DYSPHAGIA AND ON PUREED FOOD
EMBARRASSING
ENERGY LEVEL HAS NOT RESUME TO
WHAT IT WAS
EQUIVALENT OF A STROKE
EXHAUSTED AFTERWARDS
FAINT WHISPER

PULMONARY SEQUELAE OF COVID-19

FAMILY DOCTOR CONFIRMED THAT SHE WOULD BUT DID NOT FEARS OF PROGRESSIVE MENTAL DECLINE FELT LIKE A FAILURE FINANCIAL BURDEN GRADUALLY RESUMES MY ACTIVITIES GRATEFUL HAVE TO RESPECT MY LIMITS OTHERWISE I CRASH PHYSICALLY HOSPITALIZED 4 WEEKS APPEAR TO BE LAZY TO THEM I DID NOT GET THE JOB IT WAS A CONSTANT EFFORT [...] FIND SOMEONE LACK OF OXYGEN TO MY BRAIN LOSING MY VOICE WAS DIFFICULT EMOTIONALLY LOST HOPE OF EVER BEING ABLE TO WORK AGAIN LOST PART OF MY LIFE LOW ENERGY MINIMAL [...] UNDERSTANDING [...] TO SUPPORT PATIENTS MUSCLE TONE [...] NOT IMPROVED WITH PHYSICAL ACTIVITIES MY SPEECH IS AFFECTED NO LONG COVID CLINICS IN MY AREA NO LONGER [...] EXPERIENCE TROUBLE BREATHING NO SUPPORT ON BEING DISCHARGED NOT AT THE LEVEL [...] I HAD PRIOR TO COVID NOT FEELING RESTED NOTHING THAT WAS FAMILIAR IS THE SAME OUTINGS ARE TOO OVER-STIMULATING OVERWHELMED WITH SIMPLE TASKS OVERWHELMING, OVERSTIMULATING PEOPLE LOSE PATIENCE WITH ME PHYSICALLY TIRED ALL THE TIME PTSD PULMONARY FIBROSIS IN ALL LOBES OF THE LUNGS

RARELY [...] CONSIDERED [FAMILY] REAL NEED FOR LONG-COVID CLINICS REFUSED TO PRESCRIBE THE OXYGEN I NEEDED RELIEF FROM UNNECESSARY STRESS RELIEF TO REGAIN MY OWN VOICE SCAR TISSUE THE REAMINING OF MY LIFE SECOND C.T. IN SEPT 2022 REVEALED THE LUNGS WERE NOW CLEAR SMELL AND TASTE ARE STILL AFFECTED SOME DAYS ARE BETTER THAN OTHERS SOME DAYS I AM STRUGGLING [...] MORE THAN OTHERS STILL LEARNING [...] TO ADJUST AND MANAGE THESE CHANGES TALK MYSELF THROUGH IT, PRAY FOR INNER PEACE, TAKE A DEEP BREATH TEXTING HELPS THEY SUFFER WITH US FAMILY TOOK SEVERAL MONTHS TO GET [...] REFERRALS TO SPECIALISTS TRAVEL 13 HOURS TRIGGERS [...] ANY HEALTH FACILITY UNABLE TO CONTROL MY EMOTIONS UNABLE TO DO ANY HOUSEWORK UNABLE TO DRIVE UNABLE TO RETURN TO WORK UNABLE TO WALK UNIQUE IN EXPERIENCING SYMPTOMS UNPLEASANTLY PECULIAR USED OXYGEN AT NIGHT [...] AND PHYSICAL EFFORT VOICE WOULD COMPLETELY SHUT DOWN WENT UNTREATED AT EMERGENCY VISITS

**PARTICIPANT [D] 1st CYCLE IN-VIVO
CODES**

28 DAYS INTUBATED
A LOT OF PAIN IN MY BACK
AFFECTED MY FINANCES
SUBSTANTIALLY
ALL THOSE POSITIVE THINGS
ALL UPPER LUNG
ANXIOUS TO SEE THIS LUNG
SPECIALIST [...] THEY DON'T KNOW
ANY TYPE OF ACTIVITY I'VE GOT TO
HAVE THE OXYGEN
BODY PAIN IS PROBABLY THE
WORST
BREATHE, THAT'S MY FIRST
THOUGHT BREATHING IS A BIG
THING
CARRYING AROUND THE OXYGEN
[...] LIMITS A LOT
COVID PNEUMONIA ON BOTH LUNGS
CRASH ALONE
DESIRE TO GET WELL
DO I DARE GET PNEUMONIA AGAIN
EMOTIONALLY, IT'S THE HARDEST
PART
ENCOURAGEMENT THAT WE ALL
NEED
ENERGY THAT CAN BE USED
ELSEWHERE
ESSENTIAL TREMOR FROM THE
INTUBATION
FAITH HAS BEEN VERY IMPORTANT
[...] MORE LOVING
FIVE MONTHS LATER YOU GET THE
CALL
FRIENDS WHO HAVE ACTUALLY
GONE THROUGH CHEMO [...] FEEL A
LOT OF THE SAME TYPES OF THINGS
GET LOST IN WHAT WAS
GRIEF IN IT
HAD TO HIRE [...] WORK OUTSIDE
HE'S LIVING WITH LONG COVID
BECAUSE OF IT
I CAN TALK [...] IT WAS A FORCED
WHISPER
I CAN'T

I CAN'T DO THIS
I CAN'T SING
I DON'T ACCEPT INVITATIONS
EASILY
I DON'T EAT AS WELL AS I USED TO
I DON'T WANT TO END UP WITH
ADDICTION ISSUES
I HAD TO ASK FOR A LUNG
SPECIALIST
I HAD TO ASK FOR PHYSIOTHERPAY
I HAD TO PURSUE IT
I KNOW I CAN GET OUT OF THIS
I MIGHT BE GONE IN FIVE YEARS
I NEED HELP
I NEED TO BE WITH SOMEONE WHO
CAN HELP
I PAY FOR MY OXYGEN. ITS \$362 A
MONTH
I PHYSICALLY CANNOT DO THAT
I STILL AM A VOCAL COACH
I WILL DO THIS REGARDLESS OF
ENCOURAGEMENT OR NOT
I'M CAPABLE OF DOING OTHER
THINGS
I'M MEDICATED
I'M NOT BREAKING DOWN FOR YOU
I'VE GOT MAD
I'VE GOT TO DO THIS ALONE
I'VE HAD TO DO IT ALONE
I'VE LEARNED HOW TO DO THAT
DIFFERENTLY
I'VE SEEN A DIFFERENT SIDE OF
SOCIETY
IF I'M AT 90% THEY WILL NOT PAY IT
IM WORKING HARD
INSTEAD IT HAS TO GO TO THE
OXYGEN
IT HAS LIMITED ME VERY MUCH
IT'S DETERMINATION
IT'S LIKE BROKEN GLASS IN YOUR
LUNGS
ITS JUST TOO INTENSE
LEARNED HOW TO USE MY BRAIN IN
DIFFERENT WAYS

PULMONARY SEQUELAE OF COVID-19

LET GO OF THOSE LITTLE THINGS
LITTLE BIT OF FEAR
LOST RELATIONSHIPS
MERALGIA PARASHETICA
MUSCLE STRENGTH IS JUST NOT
COMING BACK
NEED TO KNOW HOW IMPORTANT
[...] TO BE ABLE TO BREATHE
NEEDS TO BE CHANGES [...] FOR
LONG COVID... BECAUSE IT'S LONG
NURSING CARE IS NOT AVAILABLE
ONE DAY AT A TIME
PHYSICALLY [...] I'M PROBABLY AT A
4 NOW
PRONING [...] THERE'S ISSUES WITH
THAT LATER
PUFFERS, NO CHANGE WHATSOEVER
PULMONARY EMBOLISMS
REALLY TAKE A LOOK AT MY GREEN
SLEEVE
REMEMBER TO PACE YOURSELF
SCARRING AND DAMAGE
SIMILAR RECONSTRUCTION AND
REPAIR AND RECOVERY
SO NEGATIVE [...] WE NEED TO SAY
YOU CAN DO THIS
TAKES TIME TO BUILD A
RELATIONSHIP TO THAT POINT
THE BEST WAY TO GET WELL
THERE'S GOT TO BE SOME REASON
WHY I DID NOT DIE
THERE'S LIFE AFTER COVID
THINGS ARE JUST NOT AVAILABLE
THIS HAS CHANGED ME A LOT AND
PEOPLE DON'T GET IT
TRAVELING
VERY STRONG FAITH
WANTED TO STAY IN BED AND NOT
TRY ANYMORE
WE NEED EVEN ONE PERSON
WHEN I WAS FIRST HOME,
ABSOLUTELY
WILL NOT EXPAND
YEAH, THIS IS ALL BECAUSE OF
COVID

YET THERE'S NOT THE ENERGY TO
DO THAT
YOU'VE GOT TO GO THROUGH THIS

PARTICIPANT [E] 1st CYCLE IN-VIVO CODES

12-18 MONTHS OF THREE
ANTIBIOTICS
ACKNOWLEDGE THAT PEOPLE
CHOOSE TO LIVE IN DIFFERENT
WAYS
ACTIVE INFECTION ON TOP OF [...]
COLONIZATION OF PSEUDOMONAS
ADVOCATE [...] MANAGE
UNCERTAINTIES
ADVOCATE FOR MYSELF BETTER
ALWAYS LOOKING FOR BLESSINGS
ANGER SURROUNDING THAT
BE RESPECTFUL OF SOMEONE WHO
PROBABLY FEELS THAT TRAUMA IN
A DIFFERENT WAY
BECOMING DANGEROUS TO MY
HEALTH
BRAIN FOG ON TOP OF EVERYTHING
BREATHE FOR [...] 10 MINUTES
BEFORE I CAN [...] HAVE A
CONVERSATION
BRONCHIECTASIS IN THE LOWER
LUNGS
BRONCHIECTASIS IS PERMANENT [...]
NEW BASELINE
COUGHING... I CAN'T STOP
COVID PNEUMONIA [...] NO ONE
REALIZED THAT I HAD
CUMULATIVE EFFECTS OF THESE
INFECTIONS
DAMAGE THAT HOLDS ON TO
BACTERIA [...] MORE DAMAGE [...] I'M
NERVOUS
DON'T HAVE THE SUPPORT OF MY
FAMILY ANYMORE
DON'T KNOW WHO WILL BE MY
HEALTH CARE AGENT
DON'T WANT THE RESPONSIBILITY
OF TEACHING

PULMONARY SEQUELAE OF COVID-19

DUE TO THE BRONCHIECTASIS FROM
THE COVID INFECTION
FIND MORE GRATITUDE IN JUST
WAKING UP
FINDING ANOTHER PROFESSIONAL
IDENTITY
GOT THE NEWS OF HAVING LUNG
DAMAGE [...] FRIENDS [...] WILL FIND
WAYS TO PROTECT YOU
HARDER TO WAKE UP [...] DON'T
HAVE A CHOICE
HELPFUL TO HAVE SOMEBODY WITH
A CHRONIC ILLNESS
HIGHER RISK OF LUNG INFECTION
HOPING [...] BY PUSHING MYSELF [...]
MAYBE GET BETTER
HOW DO I GET THE MOST OUT OF
WHAT I HAVE
I CAN BE MORE VULNERABLE WITH
HER
I CAN'T RUN ANYMORE
I FEEL SAFER
I HAVE MAC
I HAVE SO MUCH ANGER
I WAS SCARED THAT THE
PULMONARY NODULE WAS CANCER
I'M ALSO LOOKING FOR JUSTICE
I'M GOING TO BE INTUBATED IN THE
FUTURE [...] SCARIEST PART
I'VE BEEN WELL SUPPORTED
IN THE MOMENT, SEEMS TO BE
ENOUGH
IT WAS MANAGED [...] NOW WE'RE
JUST ADDING THINGS
IT'S ALL SO NEW IT'S REALLY HARD
TO GET THERE
IT'S BEEN A BIT OF A ROLLER
COASTER
JUST ACKNOWLEDGING
KEEP PUSHING THROUGH... BUT I AM
UTTERLY EXHAUSTED
LIFE JUST GOT COMPRESSED INTO A
REALLY SHORT PERIOD
MASKS [...] SLIGHTEST THING THAT
WILL BRING ME COMFORT

MUCUS PLUGGING ALL THROUGH
THE LUNGS
MULTIPLE BILATERAL NODULES
MY LIFE CHANGES AND NO ONE SEES
IT
NEBULIZE [...] PART OF THE DAILY
ROUTINE
NO ONE EVER TALKS ABOUT IS
VENTILATION
POST-IT NOTES ALL OVER THE PLACE
PROTECT OUR NEIGHBORS
PROTECT PEOPLE [...] WE COULD
VALUE LIFE AND WE DON'T
REALLY FORTUNATE [...] HAD
PEOPLE THAT WERE ALREADY
ESTABLISHED
REALLY HARD [...] THIS IS WHERE
YOU ARE [...] WHAT ARE YOU GOING
TO DO WITH IT
REALLY HELPFUL THAT SHE WAS
THE ONE TO ORDER THE CHEST X-
RAY
REGULAR FOLLOW UP [...] X-RAY
EVERY COUPLE OF YEARS
SOME OF US DIDN'T GO BACK TO
LIFE
SYMPTOMS I THOUGHT WERE LONG
COVID WERE ACTUALLY ACTIVE
INFECTION
TAKE MORE CALCULATED RISKS
TAKES SIGNIFICANTLY MORE
EFFORT
TALKING WITH PEOPLE IS HELPFUL
TELEMED IS GOING TO BE HUGE
WORRY ABOUT WHAT IT MEANS FOR
MY FUTURE

PARTICIPANT [F] 1ST CYCLE IN- VIVO CODES

6 SESSIONS TO GET THROUGH THE 45
MIN ASSESSMENT
ABANDON A LOT OF WHAT MADE
ME, ME
BRAINFOG ISN'T ONE OF MY
CHRONIC SYMPTOMS

PULMONARY SEQUELAE OF COVID-19

COMPASSION, PATIENCE, AND
UNDERSTANDING
COUGH IMPACTS MY SLEEP
DIAGNOSED WITH ASTHMA
DIAPHRAGM NO LONGER MOVES
PROPERLY
DIFFICULTY BREATHING AND A BAD
COUGH
DIFFICULTY COMPLETING
EVERYDAY ACTIVITIES
DIFFICULTY WITH SPIROMETRY
TESTING
FIGURE OUT WHERE MY TOLERANCE
LEVELS ARE
FIRST LOOK TOWARDS WHAT THE
PHYSICAL CAUSES ARE
GET TIRED VERY EASILY
HARD TIME SEEING THE FOREST FOR
THE TREES
HOW TO BETTER MONITOR AND
MANAGE MY TIME
HOW TO LIVE WITH A CHRONIC
CONDITION
CANNOT DO ACTIVITIES WITH
FRIENDS
I FAILED [...] TEST
I HAVE BEEN DENIED
ACCOMODATIONS
I HAVE GAINED WEIGHT
I OFTEN FEEL ALONE [...] I DON'T
KNOW ANYONE ELSE
I WAS SO ASHAMED
INABILITY TO BE AS PHYSICALLY
ACTIVE
LACK OF BELIEF IN COVID PERSISTS
IN SOCIETY
LACK OF SCIENTIFIC RIGOUR [...]
SNAKEOIL
MY LONG-COVID IS TOO SEVERE TO
QUALIFY FOR REHAB
NAVIGATE A WORLD THAT LOOKS
VERY DIFFERENT FROM FRIENDS
OXYGEN LEVELS CONTINUE TO
DECREASE, ITS WORRYING ME
PEOPLE SAY TO DO MORE SELF CARE
[...] WHERE DOES THIS LEAVE YOU

REALLY HORRIBLE TO BE TOLD
THAT COVID-19 IS FAKE
REMEMBER PEOPLE I HAVE LOST
BECAUSE OF COVID-19
SCIENCE DOES NOT HAVE A SOLID
UNDERSTANDING [...] VERY
DIFFICULT SO MUCH WE DON'T
KNOW [...] QUESTIONS ABOUT HOW
TO TREAT IT SPOON THEORY
STRUGGLE TO WALK UP STAIRS AND
CAN'T SLEEP
TESTS ARE INCONCLUSIVE
THE WAITLIST
TROUBLE SWALLOWING
VERTIGO TYPE ISSUES
VERY FRUSTRATED AND ALONE
VERY HARD TO MANAGE SYMPTOMS
WAITING FOR SPECIALISTS
WAITING TO SEE [...] SPECIALISTS
WISH HEALTHCARE PROFESSIONALS
[...] UNDERSTOOD THE LIVED
REALITIES
WORK IS HORRIBLE
WORKPLACE BULLYING

PARTICIPANT [G] 1ST CYCLE IN- VIVO CODES

6 MORE MONTHS TO SUFFER WITH
NO TREATMENT
ANY SORT OF DECENT INFORMATION
IS A BLESSING
BEST SUPPORT [...] FACEBOOK
BRICK ON MY CHEST
CAN'T TALK OPENLY ABOUT THIS
WITH MY FAMILY
CANNOT EVEN WALK SHORT
DISTANCES ANYMORE WITHOUT
RESTING
CONSCIOUSLY THINK ABOUT
BREATHING
COUGHING CONSTANTLY
COUGHING CONTINUES ALL DAY
DEPRESSION, ANGER, FRUSTRATION
DIFFERENTLY THE SYMPTOMS
MANIFEST BASED ON GENETICS
DO LESS, WORRY MORE

PULMONARY SEQUELAE OF COVID-19

FATIGUE CAN BE EXTREMELY
SUDDEN
FATIGUE, SIGNIFICANT REDUCTION
IN EXERCISE
GET WINDED SO QUICKLY
GIVE UP ALL THE THINGS THAT
BROUGHT YOU JOY
GOING WEEKS WITHOUT KNOWING
IS ONLY ADDING TO OUR ANXIETY
AND STRESS
GOTTEN SICKER AND SICKER
HATE NOT BEING ABLE TO DO THE
THINGS I HAVE ALWAYS DONE
HELP US GET SOME TYPE OF
TREATMENT [...] OFFER
SUGGESTIONS TO EASE THE
SUFFERING AND DISCOMFORT
HELP US GET THE APPOINTMENTS TO
SEE THE SPECIALISTS
HELP US NAVIGATE THE WAITING
GAME
HUGE DELAYS IN GETTING MEDICAL
CARE
I CAN'T REMEMBER THINGS
I HATE THE WEIGHT I HAVE GAINED
[...] MORE SEDENTARY
INTERNATIONAL ADVENTURE TRIPS
[...] COMING TO AN END
KNOWING THAT I WILL DIE OF
SUFFOCATION
LARGELY NAVIGATING THIS ALL ON
MY OWN
LITTLE [...] SUPPORT SYSTEMS
LONG INFECTIONS THAT WILL NOT
GO AWAY
MEDICAL STAFF DO NOT HAVE
SOLUTIONS
MOTIVATION IS GONE
NO ENERGY OR ENTHUSIASM TO TRY
TO FIND ALTERNATIVES
NO ISSUES UNTIL NOW
NO LEG ENDURANCE
NOTHING TO EASE THE
DISCOMFORT, ANSWER QUESTIONS,
OR HELP WITH THE ANXIETY

NURSES HAVE TENDED TO BE MORE
IN TUNE
PEOPLE ARE JUDGING ME
PEOPLE DISCOUNT THE IMPACTS
PLEASE, JUST CALL US BACK!
PRESSURE ON CHEST, STRUGGLE TO
BREATHE, WINDED EASILY
REALLY TOUGH ADJUSTMENT
RECENTLY DIAGNOSED WITH HEART
ISSUES AND COPD
SCARED ABOUT THE REDUCTION IN
LIFE EXPECTANCY
SOUL CRUSHING TO KNOW THOSE
DAYS ARE LIKELY DONE
SYMPTOMS [...] VARY DAY TO DAY
THE DUST AND WORK IS TOO MUCH
FOR ME
THINGS JUST DON'T GET DONE
USED THAT ENERGY TO GET
OUTSIDE
VITAMINS AND SUPPLEMENTS [...]
BIT MORE ENERGY
WAITS ARE SO LONG TO SEE
SPECIALISTS
WEIGHT GAIN [...] EVEN THOUGH [...]
EATING LESS

PARTICIPANT [H] 1st CYCLE IN-VIVO CODES

BREATHING [UNPLEASANT
SYMPTOMS]
CAUGHT ME OFF GUARD
DESPERATE.... TRYING ANYTHING
TO GET WELL
DIET WITHOUT ANTIHISTAMINE
DIFFERENT PUFFERS [...] WASN'Y
REALLY WORKING
DON'T KNOW WHAT TO DO WITH
YOU
FAMILY [...] REALLY CLOSE
FATIGUE, MEMORY,
CONCENTRATION, BRAIN FOG
FEELING OF DESPERATENESS
FEELS GOOD MENTALLY AND
PHYSICALLY

PULMONARY SEQUELAE OF COVID-19

GRIEVING THE PERSON THAT I WAS BEFORE
GROUP [...] TALK ABOUT WHAT WE'RE GOING THROUGH
HARD PHYSICALLY AND HARD MENTALLY
HARD TIME TO BLOW IN THAT TUBE
HARDEST FOR ME IS NOT GOING TO WORK
HIGH LEVEL OF UNCERTAINTY
I DIDN'T CURE MYSELF BECAUSE I DIDN'T REST
I NEEDED TO REST
I'M STILL WAITING
I'M USING A LOT OF SUPPLEMENTS
IMAGINE IF YOU'RE BY YOURSELF
IT'S EXHAUSTING THAT THEY DON'T UNDERSTAND
IT'S JUST HARD TO REST
LISTENING, COUNSELING [...] HAVE A PLAN WITH THEM
MORE ISOLATED
NEED SUPPORT FROM DOCTORS [...] UNDERSTAND WHAT WE'RE GOING THROUGH
NOT GOOD WITH YOUR BRAIN
NOW I HAVE TO STOP
NOWHERE TO GO [...] ALL BY MYSELF
PHYSICALLY, I WAS IN SHAPE
PROFESSIONAL THAT IS SPECIALIZED IN LONG COVID
PTSD GOING PLACES WHERE THERE'S A LOT OF PEOPLE
PUBLIC HEALTH [...] SAYING THAT IT'S NOT THEIR RESPONSIBILITY
PUBLIC HEALTH IS NOT INVOLVED
PULMONARY FUNCTION TEST WAS DOWN TO 67
PUSHING AND PUSHING
REFER YOU TO A LUNG SPECIALIST RIGHT AWAY
SATURATION WAS 84
SAW A DIFFERENCE WHEN I STARTED ANTIHISTAMINES
STARTED ASPIRIN [...] ON MY OWN THAT EXCITES ME

TRY TO HAVE A NORMAL LIFE
VERY SLOW PACE
WHEN YOU CAN'Y ANYMORE, I STOPPED
WHO I WAS AND WHO I AM NOW
WOULD LIKE PEOPLE TO WEAR MASKS
YES, A LOT [WORRY OF REINFECTION]
YOGA [...] I DIDN'T FEEL GOOD [...] TOO MUCH FOR ME RIGHT NOW

PARTICIPANT [I] 1ST CYCLE IN-VIVO CODES

BLOOD CLOTS IN LUNGS
EMOTIONALLY I AM FINE
FOUND IN ROUTINE CHECK
I FEEL IT IS BEING TAKEN SERIOUSLY
MORE AWARE OF BREATHING
ESPECIALLY AT REST
NO DIFFICULTY COMPLETING DAILY ACTIVITIES
NURSING NEEDS TO TAKE TIME TO INFORM THE PATIENT
PLACED IMMEDIATELY ON BLOOD THINNERS
RESEARCH CASE
SO MANY APPOINTMENTS
STILL QUITE ACTIVE
TAKING BLOOD THINNERS CAUSES BLEEDING

PARTICIPANT [J] 1ST CYCLE IN VIVO CODES

A LOT OF WALKING [...] COULD BARELY WALK HALF A LAP
ACHES AND PAINS IN MY JOINTS
BREATHING WAS EXTREMELY LABOURED
CAN INCREASE NOT THE LUNG FUNCTIONALITY [...] BUT WHAT I HAVE
CAN'T BE SO HARD ON YOURSELF
CANCOV RESEARCH [...] IT WAS THE DOCTOR THERE [...] XRAY

PULMONARY SEQUELAE OF COVID-19

COGNITIVE [...] THAT'S BEEN
REALLY DIFFICULT
CONSTANTLY EVOLVING
COPING HELPS YOU FUNCTION
DEGREE OF SUFFERING [...] WOULD
HAVE TO BE SOMEWHAT SIMILAR
DIDN'T EVEN COME TO MY
THOUGHTS THAT MAYBE MY LUNGS
WERE REALLY DAMAGED
DON'T KNOW WHAT'S GOING ON
WITH YOU ANYMORE
EDUCATION ON YOUR LUNG DISEASE
EXACTLY HOW I FELT
EXHAUSTED [...] RIGHT AWAY
FINANCIAL AND EMPLOYMENT
ISSUES [...] HARD TO COGNITIVELY
THINK
FOREVER A DIFFERENT PERSON
GENERAL PRACTITIONER [...] THAT'S
ALL I EVER HEARD
GIVEN MY DAUGHTER AN EXTREME
SENSE OF ANXIETY
GOT TO PUSH MYSELF [...] NO, THATS
NOW HOW YOU DO IT
HARD TIME FINDINGS WORDS
HASN'T GOTTEN WORSE [...] POSITIVE
THING
HOW TO COPE, HOW TO MANAGE
I DON'T RECALL THEM OFFERING IT
I HAD TO LEARN HOW...
I NEED TO KNOW THINGS [...] SO
THAT I CAN GET BETTER
I RUN OUT OF BREATH LIKE OFTEN
INSIGHT INTO WHAT I HAVE GOING
ON IN MY BODY
LITTLE RESENTFUL
LUNG FUNCTION IS AT 69%
LUNG FUNCTION TEST [...] EVERY
SIX MONTHS
MENTALITY OF [...] I'LL PUSH
MORE GROUP SITUATIONS [...]
SIMILAR SITUATIONS
MY VOICE [...] HARD TO
COMMUNICATE
NEVER HAD ANYBODY [...] EXPLAIN
HOW RECOVERY WORKS

ONLY ONE [...] WITH MY SITUATION
THERE
OXYGEN FOR PROBABLY ABOUT A
MONTH
PARTICIPATING IN EVERYTHING
THAT'S OFFERED IS MORE
BENEFICIAL THAN PEOPLE THINK
PROGRESSED UNBELIEVABLY IN
THESE LAST [...] MONTHS THAN I DID
IN THAT WHOLE LAST YEAR
PULMONARY FIBROSIS
PULMONARY REHAB AND ANOTHER
[...] COGNITIVE FOR COVID
PUSH THROUGH [...] YOU CAN'T DO
THAT WITH THIS, IT'S DIFFERENT
REFUSE FOR IT TO BECOME ALL
ABOUT ME AND THAT THIS IS OUR
LIFE NOW
SLEEP IS GREAT
SLOW AND STEADY
STARTED WITH THE MOST
IMPORTANT THING OF THE DAY
STAYING OPTIMISTIC
TALK THERAPY [...] IS A BIG THING
THANKFUL FOR THAT
THAT THERAPY DID WORK
THAT WAS JUST A STAGE [...]
STARTING WHEN YOU GET HOME
THE NUMBER ONE THING, IT'S THE
EXHAUSTION THEY COULD HAVE
HELPED ME ADAPT [...] SELF CARE
TIRING TO EXPLAIN YOUR
SITUATION
TOOLS YOU NEED TO [...] FIND YOUR
NEW NORMAL
WALK ABOUT 50 FEET
WHEN I CAME HOME, I THOUGHT,
OK, I'M DONE WHEN I GOT HOME [...]
THAT'S HOW WEAK MY BODY WAS
WORK [...] IT'S GONE NOW
WOULD BE NICE TO JUST [...] SHARE
YOU'RE JUST STARTING

Appendix G: Coding Chart Categories

A LOT MORE APPOINTMENTS
APPOINTMENT TIMES
LONG WAIT UP TO SIX MONTHS
LONG WAITING FOR APPOINTMENTS
THREE MONTHS LATER
HAVEN'T SEEN THE RESULTS
I DON'T HAVE A FAMILY DOCTOR
INTEGRATED POST COVID
NAVIGATIONAL TEAM
MONTHLY IRON TRANSFUSION
SYSTEM THAT YOU KIND OF HAVE
TO GO THROUGH
DID NOT REFER ME TO A
RESPIROLOGIST
DOCTORS SUPPORT WOULD HAVE
BEEN A TREMENDOUS HELP
FAMILY DOCTOR CONFIRMED THAT
SHE WOULD BUT DID NOT
IT WAS A CONSTANT EFFORT [...]
FIND SOMEONE
MINIMAL [...] UNDERSTANDING [...]
TO SUPPORT PATIENTS
NO LONG COVID CLINICS IN MY
AREA
NO SUPPORT ON BEING DISCHARGED
REAL NEED FOR LONG COVID
CLINICS
REFUSED TO PRESCRIBE THE OXYGEN
NEEDED
TOOK SEVERAL MONTHS TO GET [...]
REFERRALS TO SPECIALISTS
TRAVEL 13 HOURS
WENT UNTREATED AT EMERGENCY
VISITS
ANXIOUS TO SEE THIS LUNG
SPECIALIST [...] THEY DON'T KNOW
FIVE MONTHS LATER YOU GET THE
CALL
I HAD TO ASK FOR A LUNG
SPECIALIST
I HAD TO ASK FOR PHYSIOTHERAPY
I HAD TO PURSUE IT
I NEED HELP

NEEDS TO BE CHANGES [...] FOR
LONG COVID... BECAUSE IT'S LONG
12-18 MONTHS OF THREE
ANTIBIOTICS
I CAN BE MORE VULNERABLE WITH
HER
REALLY FORTUNATE [...] HAD
PEOPLE THAT WERE ALREADY
ESTABLISHED
REALLY HELPFUL THAT SHE WAS
THE ONE TO ORDER THE CHEST X-
RAY
REGULAR FOLLOW UP [...] XRAY
EVERY COUPLE OF YEARS
THE WAITLIST
WAITING FOR SPECIALISTS
WAITING TO SEE [...] SPECIALISTS
6 MORE MONTHS TO SUFFER WITH
NO TREATMENT
GOING WEEKS WITHOUT KNOWING
IS ONLY ADDING TO OUR ANXIETY
AND STRESS
HUGE DELAYS IN GETTING MEDICAL
CARE
WAITS ARE SO LONG TO SEE
SPECIALISTS
I'M STILL WAITING
NEED SUPPORT FROM DOCTORS [...]
UNDERSTAND WHAT WE'RE GOING
THROUGH
REFER YOU TO A LUNG SPECIALIST
RIGHT AWAY
FOUND IN ROUTINE CHECK
RESEARCH CASE
SO MANY APPOINTMENTS
CANCOV RESEARCH [...] IT WAS THE
DOCTOR THERE [...] XRAY
GENERAL PRACTITIONER [...] THAT'S
ALL I EVER HEARD

**DEEPEST STRUGGLE IS NOT
HAVING THE ENERGY + FATIGUE
CAN BE EXTREMELY SUDDEN + NO
ENERGY OR ENTHUSIASM TO TRY**

**TO FIND ALTERNATIVES +
STARTED WITH THE MOST
IMPORTANT THING OF THE DAY**
CAN'T DO THAT ANYMORE
DEPENDS ON THE ACTIVITY
EXERT MYSELF
I WAS VERY ACTIVE
PHYSICALLY, I WAS IN SHAPE
MORE EXERTION THAN USUAL
NAP FOR 3 OR 4 HOURS
WALK AT A SLOW PACE
WOULDN'T BE EXERTING MYSELF
ENJOYING MY READING AND YOGA
I DO MISS MY RUNNING
BREATHING TEST REALLY DIFFICULT
SICK FOR A FEW DAYS AFTER
[BREATHING TEST]
I HAVE TAKEN UP YOGA
SHORTNESS OF BREATH RIGHT
AWAY
I DON'T THINK I NEED THAT MUCH
SLEEP
I DON'T HAVE ANY OF THAT [BRAIN
FOG]
BRAIN FOG
BREATHING PROBLEMS SINCE
ANEMIC NOW [BLOOD THINNERS]
COMPLETELY KNOCKED OUT
DIFFICULTY TO DO THE DEEP
BREATHS
EASIER HOBBIES
HATE DOING YOGA
HAVING TROUBLE SLEEPING
IT'S JUST SO EXHAUSTING
MORE ACTIVITY THAN USUAL
REALLY HARD TIME
THEY ARE VERY PAINFUL [YOGA
BREATHING]
TWICE AS LONG AS IT WOULD IN THE
PAST
VERY DIFFICULT TIME ACTUALLY
DOING THE BREATHING TEST
WHY CAN'T I DO THIS
ACTIVITIES I AM NO LONGER ABLE
TO TAKE PART IN
AFFECTS MY COGNITIVE ABILITIES

CAN'T FOCUS... TRIGGERS ANXIETY
AND PANIC
COGNITIVE IMPAIREMENTS [...]
SENSE OF FAILURE AND DEFEAT
DIFFICULTIES EXPRESSING A
THOUGHT
ENERGY LEVEL HAS NOT RESUME TO
WHAT IT WAS
EXHAUSTED AFTERWARDS
GRADUALLY RESUME MY
ACTIVITIES
HAVE TO RESPECT MY LIMITES
OTHERWISE I CRASH PHYSICALLY
LACK OF OXYGEN TO MY BRAIN
LOW ENERGY
MUSCLE TONE [...] NOT IMPROVED
WITH PHYSICAL ACTIVITIES
NOT AT THE LEVEL [...] I HAD PRIOR
TO COVID
NOT FEELING RESTED
OUTINGS ARE TOO OVER-
STIMULATING
OVERWHELMED WITH SIMPLE TASKS
OVERWHELMING,
OVERSTIMULATING
PHYSICALLY TIRED ALL THE TIME
UNABLE TO DO ANY HOUSEWORK
UNABLE TO DRIVE
UNABLE TO WALK
ANY TYPE OF ACTIVITY I'VE GOT TO
HAVE THE OXYGEN
ENERGY THAT CAN BE USED
ELSEWHERE
I CAN'T DO THIS
I PHYSICALLY CANNOT DO THAT
I'M CAPABLE OF DOING OTHER
THINGS
IT HAS LIMITED ME VERY MUCH
IT'S JUST TOO INTENSE
MUSCLE STRENGTH IS JUST NOT
COMING BACK
PHYSICALLY [...] I'M PROBABLY AT A
4 NOW
REMEMBER TO PACE YOURSELF
WANTED TO STAY IN BED AND NOT
TRY ANYMORE

PULMONARY SEQUELAE OF COVID-19

YET THERE'S NOT THE ENERGY TO
DO THAT
BRAIN FOG ON TOP OF EVERYTHING
HARDER TO WAKE UP [...] DON'T
HAVE A CHOICE
I CAN'T RUN ANYMORE
TAKES SIGNIFICANTLY MORE
EFFORT
6 SESSIONS TO GET THROUGH THE 45
MIN ASSESSMENT
BRAIN FOG ISN'T ONE OF MY
CHRONIC SYMPTOMS
DIFFICULTY COMPLETING
EVERYDAY ACTIVITIES
DIFFICULTY WITH SPIROMETRY
TESTING
GET TIRED VERY EASILY
CANNOT DO ACTIVITIES WITH
FRIENDS
I FAILED [...] TEST
INABILITY TO BE AS PHYSICALLY
ACTIVE
SPOON THEORY
STRUGGLE TO WALK UP STAIRS AND
CAN'T SLEEP
VERTIGO TYPE ISSUES
CANNOT EVEN WALK SHORT
DISTANCES ANYMORE WITHOUT
RESTING
FATIGUE, SIGNIFICANT REDUCTION
IN EXERCISE
GET WINDED SO QUICKLY
GOTTEN SICKER AND SICKER
I CAN'T REMEMBER THINGS
I HATE THE WEIGHT I HAVE GAINED
[...] MORE SEDENTARY
NO LEG ENDURANCE
THINGS JUST DON'T GET DONE
USED THAT ENERGY TO GET
OUTSIDE
VITAMINS AND SUPPLEMENTS [...]
BIT MORE ENERGY
WEIGHT GAIN [...] EVEN THOUGH [...]
EATING LESS
FATIGUE, MEMORY,
CONCENTRATION, BRAIN FOG

FEELS GOOD MENTALLY AND
PHYSICALLY [LIGHT WALKING]
HARD PHYSICALLY AND HARD
MENTALLY
HARD TIME TO BLOW IN THAT TUBE
NOT GOOD WITH YOUR BRAIN
NOW I HAVE TO STOP
VERY SLOW PACE
WHEN YOU CAN'T ANYMORE, I
STOPPED
YOGA [...] DIDN'T FEEL GOOD [...] TOO
MUCH FOR ME RIGHT NOW
STILL QUITE ACTIVE
A LOT OF WALKING [...] COULD
BARELY WALK HALF A LAP
COGNITIVE [...] THAT'S BEEN REALLY
DIFFICULT
EXHAUSTED RIGHT AWAY
SLEEP IS GREAT
SLOW AND STEADY
TIRING TO EXPLAIN YOUR
SITUATION
WALK ABOUT 50 FEET

ALWAYS HAVE MY VENTOLIN
TWO INHALERS THAT I USE NOW
DIDN'T REALIZE HOW MUCH THE
VENTOLIN HELPS
INHALERS HELPED ME A LOT
WOULDN'T BE ABLE TO DO IT
WITHOUT MY INHALERS
PEAK FLOW METER
HELPED WITH THE OPENING UP MY
LUNGS
I DO HAVE A PUFFER
TEND TO FORGET IT [PUFFER]
PUFFERS, NO CHANGE WHATSOEVER
DIFFERENT PUFFERS [...] WASN'T
REALLY WORKING

FRUSTRATED WITH ME
AWKWARD AND EMBARRASING
SITUATION
EMBARRASING
FELT LIKE A FAILURE
APPEAR TO BE LAZY TO THEM

PULMONARY SEQUELAE OF COVID-19

PEOPLE LOSE PATIENCE WITH ME
THIS HAS CHANGED ME A LOT AND
PEOPLE DON'T GET IT
YEAH, THIS IS ALL BECAUSE OF
COVID
MY LIFE CHANGES AND NO ONE SEES
IT
I WAS SO ASHMAED
PEOPLE ARE JUDGING ME
PEOPLE DISCOUNT THE IMPACTS
HARD TIME FINDING WORDS

NO ONE HAS ANY ANSWERS
NO ONE KNOWS
NO ONE REALLY KNOWS
IT'S ALL SO NEW IT'S REALLY HARD
TO GET THERE
SCIENCE DOES NOT HAVE A SOLID
UNDERSTANDING [...] VERY
DIFFICULT
SO MUCH WE DON'T KNOW [...]
QUESTIONS ABOUT HOW TO TREAT
IT
MEDICAL STAFF DO NOT HAVE
SOLUTIONS
DON'T KNOW WHAT TO DO WITH
YOU
IT'S EXHAUSTING THAT THEY DON'T
UNDERSTAND
I FEEL IT IS BEING TAKEN SERIOUSLY
DON'T KNOW WHAT'S GOING ON
WITH YOU ANYMORE

GOOD DAYS AND BAD DAYS
HANDLING THIS OK ON MY OWN
I'M A FAIRLY INDEPENDENT PERSON
I'M A POSITIVE PERSON
I'M ALSO HOPEFUL
I'M DOING GOOD
LITTLE BIT BETTER
POSITIVE SPIN ON IT
CONSIDER MYSELF VERY LUCKY
DIFFICULT BUT STILL MANAGEABLE
THE LITTLE THINGS
I DO GET TO CONTINUE TO LIVE
NOT QUITE AS BAD AS IT WAS

ON TOP OF SOMETHING I WAS ABLE
TO COPE WITH
VERY GRATEFUL FOR WHAT I HAVE
GRATEFUL
SOME DAYS ARE BETTER THAN
OTHERS
SOME DAYS I AM STRUGGLING [...]
MORE THAN OTHERS
ALL THOSE POSITIVE THINGS
I KNOW I CAN GET OUT OF THIS

LUNGS ARE ALREADY REALLY BAD
BLOOD CLOTS IN MY LUNGS
DEEP PAIN [LUNGS]
HYPERINFLATION OF THE LUNGS
IN THE TRASH [BREATHING]
LUNG CAPACITY
MY DIAPHRAGM HURTS
PNEUMONIA IN MY LUNG AND FLUID
SEVERE PAIN IN MY LUNGS
NO LONGER [...] EXPERIENCE
TROUBLE BREATHING
PULMONARY FIBROSIS IN ALL LOBES
OF THE LUNGS
SCAR TISSUE THE REMAINING OF MY
LIFE
SECOND C.T. IN SEPT 2022 REVEALED
THE LUNGS WERE NOW CLEAR
USED OXYGEN AT NIGHT [...] AND
PHYSICAL EFFORT
ALL UPPER LUNG
COVID PNEUMONIA ON BOTH LUNGS
IT'S LIKE BROKEN GLASS IN YOUR
LUNGS
PULMONARY EMBOLISMS
SCARRING AND DAMAGE
WILL NOT EXPAND
I HAVE MAC (mycobacterium avium
complex)
ACTIVE INFECTION ON TOP OF [...]
COLONIZATION OF PSEUDOMONAS
BECOMING DANGEROUS TO MY
HEALTH
BRONCHIECTASIS IN THE LOWER
LUNGS

PULMONARY SEQUELAE OF COVID-19

BRONCHIECTASIS IS PERMANENT [...] NEW BASELINE
COUGHING... I CAN'T STOP
COVID PNEUMONIA [...] NO ONE REALIZED THAT I HAD
CUMULATIVE EFFECTS OF THESE INFECTIONS
DAMAGE THAT HOLDS ON TO BACTERIA [...] MORE DAMAGE [...] I'M NERVOUS
DUE TO THE BRONCHIECTASIS FROM THE COVID INFECTION
HIGHER RISK OF LUNG INFECTION
I WAS SCARED THAT THE PULMONARY NODULE WAS CANCER
MUCUS PLUGGING ALL THROUGH THE LUNGS
MULTIPLE BILATERAL NODULES
SYMPTOMS I THOUGHT WERE LONG COVID WERE ACTUALLY ACTIVE
INFECTION
DIAGNOSED WITH ASTHMA
OXYGEN LEVELS CONTINUE TO DECREASE, ITS WORRYING ME
TESTS ARE INCONCLUSIVE
LONG INFECTIONS THAT WILL NOT GO AWAY
NO ISSUES UNTIL NOW
RECENTLY DIAGNOSED WITH HEART ISSUES AND COPD
THE DUST AND WORK IS TOO MUCH FOR ME
CAUGHT ME OFF GUARD
PULMONARY FUNCTION TEST WAS DOWN TO 67
SATURATION WAS 84
YES, A LOT [WORRY OF REINFECTION]
BLOOD CLOTS IN LUNGS
PLACED IMMEDIATELY ON BLOOD THINNERS
DIDN'T EVEN COME TO MY THOUGHTS THAT MAYBE MY LUNGS WERE REALLY DAMAGED
LUNG FUNCTION IS AT 69%

LUNG FUNCTION TEST [...] EVERY SIX MONTHS
PULMONARY FIBROSIS

DID NOT SOUND LIKE MY VOICE AT ALL

DYSPHAGIA AND ON PUREED FOOD
FAINT WHISPER
LOSING MY VOICE WAS DIFFICULT EMOTIONALLY
MY SPEECH IS AFFECTED
RELIEF TO REGAIN MY VOICE
VOICE WOULD COMPLETELY SHUT OWN
I CAN TALK [...] IT WAS A FORCED WHISPER
I CAN'T SING
I STILL AM A VOCAL COACH
TROUBLE SWALLOWING
MY VOICE [...] HARD TO COMMUNICATE

PARANOID AT FIRST

NERVOUS TO GET IT AGAIN
A LOT MORE CAREFUL THAN I HAVE IN THE PAST
DOESN'T MAKE ME AFRAID OF DEATH
STOP BEING A VICTIM
FEARS OF PROGRESSIVE MENTAL DECLINE
DO I DARE GET PNEUMONIA AGAIN
LITTLE BIT OF FEAR

NURSES HAVE TENDED TO BE MORE IN TUNE + PROFESSIONAL THAT IS SPECIALIZED IN LONG COVID

BE A NURSE FOR THE RIGHT REASONS
CARE AND COMPASSION
DETAILS AND INTRICACIES I FEEL IS VERY IMPORTANT
LISTEN AND UNDERSTAND
SHE KNOWS WHAT SHES DOING AND I'M SAFE HERE

PULMONARY SEQUELAE OF COVID-19

SOMEONE ACTUALLY LISTENED
[POST COVID NAVIGATION TEAM]
VALIDATED IT
DEGREE OF UNDERSTANDING
RELIEF FROM UNNECESSARY STRESS
DESIRE TO GET WELL [THEY WOULD
HAVE TO KNOW]
ENCOURAGEMENT THAT WE ALL
NEED
I NEED TO BE WITH SOMEONE WHO
CAN HELP [POST-DISCHARGE]
NEED TO KNOW HOW IMPORTANT [...]
TO BE ABLE TO BREATHE
TAKES TIME TO BUILD A
RELATIONSHIP TO THAT POINT
WE NEED EVEN ONE PERSON
WHEN I WAS FIRST HOME,
ABSOLUTELY
ACKNOWLEDGE THAT PEOPLE
CHOSE TO LIVE IN DIFFERENT WAYS
BE RESPECTFUL OF SOMEONE WHO
PROBABLY FEELS THAT TRAUMA IN
A DIFFERENT WAY
JUST ACKNOWLEDGING
COMPASSION, PATIENCE, AND
UNDERSTANDING
WISH HEALTHCARE PROFESSIONALS
[...] UNDERSTOOD THE LIVED
REALITIES
EDUCATION ON YOUR LUNG DISEASE

**HELP US GET SOME TYPE OF
TREATMENT [...] OFFER
SUGGESTIONS TO EASE THE
SUFFERING AND DISCOMFORT**
HELP US GET THE APPOINTMENTS TO
SEE THE SPECIALISTS
HELP US NAVIGATE THE WAITING
GAME
NURSING CARE IS NOT AVAILABLE
THINGS ARE JUST NOT AVAILABLE
TELEMED IS GOING TO BE HUGE
ANY SORT OF DECENT INFORMATION
IS A BLESSING
PLEASE, JUST CALL US BACK!

LISTENING, COUNSELING [...] HAVE
PLAN
NURSING NEEDS TO TAKE TIME TO
INFORM THE PATIENT
I DON'T RECALL THEM OFFERING IT
NEVER HAD ANYBODY [...] EXPLAIN
HOW RECOVERY WORKS
TALK THERAPY [...] IS A BIG THING
THEY COULD HAVE HELPED ME
ADAPT [...] SELF-CARE
TOOLS YOU NEED TO [...] FIND YOUR
NEW NORMAL

PUBLIC HEALTH IS NOT INVOLVED
PUBLIC HEALTH [...] SAYING THAT
IT'S NOT THEIR RESPONSIBILITY

FAMILY
RARELY [...] CONSIDERED [FAMILY]
THEY SUFFER WITH US
HE'S LIVING WITH LONG COVID
BECAUSE OF IT
LOST RELATIONSHIPS
DON'T HAVE THE SUPPORT OF MY
FAMILY ANYMORE
GOT THE NEWS ABOUT HAVING
LUNG DAMAGE [...] FRIENDS [...] WILL
FIND WAYS TO PROTECT YOU
PROTECT OUR NEIGHBORS
CAN'T TALK OPENLY ABOUT THIS
WITH MY FAMILY
FAMILY [...] REALLY CLOSE
MORE ISOLATED
GIVEN MY DAUGHTER AN EXTREME
SENSE OF ANXIETY

I'VE BEEN LET GO [EMPLOYER]
INTERSECTIONALITY
NOT REALLY ROOM FOR PEOPLE IN
GENERAL WITH DISABILITIES
I DID NOT GET THE JOB
LOST HOPE OF EVER BEING ABLE TO
WORK AGAIN
UNABLE TO RETURN TO WORK
FINDING ANOTHER PROFESSIONAL
IDENTITY

PULMONARY SEQUELAE OF COVID-19

I HAVE BEEN DENIED
ACCOMODATIONS
WORK IS HORRIBLE
WORKPLACE BULLYING
HARDEST FOR ME IS NOT GOING TO
WORK
FINANCIAL AND EMPLOYMNET
ISSUES [...] HARD TO COGNITIVELY
THINK
WORK [...] IT'S GONE NOW

IT'S A NEW SCARY WORLD
AVOID PHONE CALLS OR BEING
WITH PEOPLE
NOTHING THAT WAS FAMILIAR IS
THE SAME
UNPLEASANTLY PECULIAR
I DON'T ACCEPT INVITATIONS
EASILY
I'VE SEEN A DIFFERENT SIDE OF
SOCIETY
PROTECT PEOPLE [...] WE COULD
VALUE LIFE AND WE DON'T
SOME OF US DIDN'T GO BACK TO
LIFE
REALLY HORRIBLE TO BE TOLD
THAT COVID-19 IS FAKE
PTSD GOING PLACES WHERE
THERE'S A LOT OF PEOPLE

FINNANCIAL BURDEN
AFFECTED MY FINANCES
SUBSTANTIALLY
I DON'T EAT AS WELL AS I USED TO
I PAY FOR MY OXYGEN, IT'S \$362 A
MONTH
IF I'M AT 90% THEY WILL NOT PAY IT
INSTEAD IT HAS TO GO TO THE
OXYGEN

LOST PART OF MY LIFE
28 DAYS INTUBATED

**STILL LEARNING [...] TO ADJUST
AND MANAGE THESE CHANGES +
THERE'S LIFE AFTER COVID + TRY**

**TO HAVE A NORMAL LIFE + THAT
WAS JUST A STAGE [...] STARTING
WHEN YOU GET HOME + WHEN I
CAME HOME, I THOUGHT, OK, I'M
DONE**
TALK MYSELF THROUGH IT, PRAY
FOR INNER PEACE, TAKE A DEEP
BREATH
TEXTING HELPS
TRIGGERS [...] ANY HEALTH
FACILITY
UNABLE TO CONTROL MY EMOTIONS
CARRYING AROUND THE OXYGEN
[...] LIMITS A LOT
ESSENTIAL TREMOR FROM THE
INTUBATION
FRIENDS WHO HAVE ACTUALLY
GONE THROUGH CHEMO [...] FEEL A
LOT OF THE SAME TYPES OF THINGS
SIMILAR RECONSTRUCTION AND
REPAIR AND RECOVERY
HAD TO HIRE [...] WORK OUTSIDE
I WILL DO THIS REGARDLESS OF
ENCOURAGEMENT OR NOT
I'VE LEARNED HOW TO DO THAT
DIFFERENTLY
I'M WORKING HARD
IT'S DETERMINATION
LEARNED HOW TO USE MY BRAIN IN
DIFFERENT WAYS
LET GO OF THOSE LITTLE THINGS
ONE DAY AT A TIME
SO NEGATIVE [...] WE NEED TO SAY
YOU CAN DO THIS
YOU'VE GOT TO GO THROUGH THIS
ADVOCATE [...] MANAGE
UNCERTAINTIES
ADVOCATE FOR MYSELF BETTER
DON'T WANT THE RESPONSIBILITY
OF TEACHING
IT WAS MANAGED [...] NOW WE'RE
JUST ADDING THINGS
MASKS [...] SLIGHTEST THING THAT
WILL BRING ME COMFORT
NEBULIZE [...] PART OF THE DAILY
ROUTINE

PULMONARY SEQUELAE OF COVID-19

POST-IT NOTES ALL OVER THE PLACE
REALLY HARD [...] THIS IS WHERE
YOU ARE [...] WHAT ARE YOU GOING
TO DO WITH IT
TAKE MORE CALCULATED RISKS
FIGURE OUT WHERE MY TOLERANCE
LEVELS ARE
HARD TIME SEEING THE FOREST FOR
THE TREES
HOW TO BETTER MONITOR AND
MANAGE MY TIME
HOW TO LIVE WITH A CHRONIC
CONDITION
NAVIGATE A WORLD THAT LOOKS
VERY DIFFERENT FROM FRIENDS
PEOPLE SAY TO DO MORE SELF CARE
[...] WHERE DOES THIS LEAVE YOU
VERY DIFFICULT TO MANAGE
SYMPTOMS
BEST SUPPORT [...] FACEBOOK
DO LESS, WORRY MORE
HATE NOT BEING ABLE TO DO THE
THINGS I HAVE ALWAYS DONE
NOTHING TO EASE THE
DISCOMFORT, ANSWER QUESTIONS,
OR HELP WITH THE ANXIETY
SYMPTOMS [...] VARY DAY TO DAY
DESPERATE... TRYING ANYTHING TO
GET WELL
DIET WITHOUT ANTIHISTAMINE
FEELING OF DESPERATENESS
GROUP [...] TALK ABOUT WHAT
WE'RE GOING THROUGH
HIGH LEVEL OF UNCERTAINTY
I'M USING A LOT OF SUPPLEMENTS
SAW A DIFFERENCE WHEN I
STARTED ANTIHISTAMINES
STARTED ASPIRIIN [...] ON MY OWN
WOULD LIKE PEOPLE TO WEAR
MASKS
NO DIFFICULTY COMPLETING DAILY
ACTIVITIES
TAKING BLOOD THINNERS CAUSES
BLEEDING
CAN'T BE SO HARD ON YOURSELF
COPING HELPS YOU FUNCTION

FOREVER A DIFFERENT PERSON
HOW TO COPE, HOW TO MANAGE
I HAD TO LEARN HOW...
I NEED TO KNOW THINGS [...] SO
THAT I CAN GET BETTER
PARTICIPATING IN EVERYTHING
THAT'S OFFERED IS MORE
BENEFICIAL THAN PEOPLE THINK
REFUSE FOR IT TO BECOME ALL
ABOUT ME AND THAT THIS IS OUR
LIFE NOW
WHEN I GOT HOME [...] THAT'S HOW
WEAK MY BODY WAS
YOU'RE JUST STARTING

BODY PAIN IS PROBABLY THE WORST

A LOT OF PAIN IN MY BACK
I'M MEDICATED
I DON'T WANT TO END UP WITH
ADDICTION ISSUES
MERALGIA PARASHETICA
PRONING [...] THERE'S ISSUES WITH
THAT LATER
ACHES AND PAINS IN MY JOINTS

BREATHING IS A BIG THING

BREATHE, THAT'S MY FIRST
THOUGHT
BREATHE FOR [...] 10 MINUTES
BEFORE I CAN [...] HAVE A
CONVERSATION
NO ONE EVER TALKS ABOUT IS
VENTILATION
DIAPHRAGM NO LONGER MOVES
PROPERLY
DIFFICULTY BREATHING AND A BAD
COUGH
BRICK ON MY CHEST
CONSCIOUSLY THINK ABOUT
BREATHING
COUGHING CONSTANTLY
COUGHING CONTINUES ALL DAY
PRESSURE ON CHEST, STRUGGLE TO
BREATHE, WINDED EASILY

PULMONARY SEQUELAE OF COVID-19

BREATHING [UNPLEASANT SYMPTOMS]
MORE AWARE OF BREATHING
ESPECIALLY AT REST
BREATHING WAS EXTREMELY
LABOURED
CAN INCREASE NOT THE LUNG
FUNCTIONALITY [...] BUT WHAT I
HAVE
I RUN OUT OF BREATH LIKE OFTEN
OXYGEN FOR PROBABLY ABOUT A
MONTH

I'VE GOT TO DO THIS ALONE
CRASH ALONE
HELPFUL TO HAVE SOMEBODY WITH
A CHRONIC ILLNESS
TALKING WITH PEOPLE IS HELPFUL
I OFTEN FEEL ALONE [...] I DON'T
KNOW ANYONE ELSE
VERY FRUSTRATED AND ALONE
LARGELY NAVIGATING THIS ALL ON
MY OWN
LITTLE [...] SUPPORT SYSTEMS
IMAGINE YOU'RE BY YOURSELF
NOWHERE TO GO [...] ALL BY MYSELF

**EMOTIONALLY, IT'S THE HARDEST
PART**
GET LOST IN WHAT WAS
GRIEF IN IT
I'M NOT BREAKING DOWN FOR YOU
I'VE GOT MAD
ANGER SURROUNDING THAT
I HAVE SO MUCH ANGER
I'M ALSO LOOKING FOR JUSTICE
IT'S BEEN A BIT OF A ROLLER
COASTER
ABANDON A LOT OF WHAT MADE
ME, ME
REMEMBER PEOPLE I HAVE LOST
BECAUSE OF COVID-19
DEPRESSION, ANGER, FRUSTRATION
GIVE UP ALL THE THINGS THAT
BROUGHT YOU JOY

INTERNATIONAL ADVENTURE TRIPS
[...] COMING TO AN END
MOTIVATION IS GONE
SOUL CRUSHING TO KNOW THOSE
DAYS ARE LIKELY DONE
GRIEVING THE PERSON THAT I WAS
BEFORE
WHO I WAS AND WHO I AM NOW
EMOTIONALLY I AM FINE
LITTLE RESENTFUL

ALWAYS LOOKING FOR BLESSINGS
FAITH HAS BEEN VERY IMPORTANT
[...] MORE LOVING
THERE'S GOT TO BE SOME REASON
WHY I DID NOT DIE
VERY STRONG FAITH
FIND MORE GRATITUDE IN JUST
WAKING UP
HOW DO I GET THE MOST OUT OF
WHAT I HAVE
IN THE MOMENT, SEEMS TO BE
ENOUGH
THAT EXCITES ME [LONG COVID
CLINIC]
CONSTANTLY EVOLVING
HASN'T GOTTEN WORSE [...] POSITIVE
THING
STAYING OPTIMISITIC

**I'M GOING TO BE INTUBATED IN
THE FUTURE [...] SCARIEST PART**
I MIGHT BE GONE IN FIVE YEARS
REALLY TAKE A LOOK AT MY GREEN
SLEEVE
DON'T KNOW WHO WILL BE MY
HEALTH CARE AGENT
LIFE JUST GOT COMPRESSED INTO A
REALLY SHORT PERIOD
WORRIED ABOUT WHAT IT MEANS
FOR MY FUTURE
KNOWING THAT I WILL DIE OF
SUFFOCATION
SCARED ABOUT THE REDUCTION IN
LIFE EXPECTANCY

**PUSH THROUGH [...] YOU CAN'T DO
THAT WITH THIS, IT'S DIFFERENT
GOT TO PUSH MYSELF [...] NO,
THAT'S NOT HOW YOU DO IT
HOPING [...] BY PUSHING MYSELF [...]
MAYBE GET BETTER
KEEP PUSHING THROUGH... BUT I AM
UTTERLY EXHAUSTED
PUSHING AND PUSHING
I DIDN'T CURE MYSELF BECAUSE I
DIDN'T REST
I NEED TO REST
IT'S JUST HARD TO REST
MENTALITY OF [...] I'LL PUSH**

**FIRST LOOK TOWARD WHAT THE
PHYSICAL CAUSES ARE
LACK OF SCIENTIFIC RIGOUR [...]
SNAKEOIL
DIFFERENTLY THE SYMPTOMS
MANIFEST BASED ON GENETICS**

INSIGHT INTO WHAT I HAVE GOING
ON IN MY BODY

**MY LONG-COVID IS TOO SEVERE
TO QUALIFY FOR REHAB**

**DEGREE OF SUFFERING [...] WOULD
HAVE TO BE SOMEWHAT SIMILAR
EXACTLY HOW I FELT
MORE GROUP SITUATIONS [...]
SIMILAR SITUATIONS
ONLY ONE [...] WITH MY SITUATION
THERE
WOULD BE NICE TO JUST [...] SHARE**

**PULMONARY REHAB AND
ANOTHER [...] COGNITIVE FOR
COVID
PROGRESSED UNBELIEVABLY IN THE
LAST [...] MONTHS THAN I DID IN
THAT WHOLE LAST YEAR
THAT THERAPY DID WORK**

Appendix H: Example of Analytic Memo Writing

Prior to developing acute COVID-19, most participants describe an energetic and active physical baseline [***“I WAS VERY ACTIVE”; PHYSICALLY, I WAS IN SHAPE”; “I COULD LITERALLY RUN HOME IN 6 MINUTES FLAT”; “I WAS PLANNING ON DOING A HALF MARATHON”; “I USED TO SWIM 1H/DAY, 7 DAYS/WEEK PRIOR TO COVID”; “VIGOROUS INTERNATIONAL ADVENTURE TRIPS”; GOING TO THE GYM 5 TO 6 TIMES A WEEK [...] SPORTS, HIKING, CANOEING, BIKING”***]. As a starting point to understanding these realities, participants expressed concern similar to Turner et al. (2023), calling for the identification of physical causes of long-COVID [***“FIRST LOOK TOWARD WHAT THE PHYSICAL CAUSES ARE”; “INSIGHT INTO WHAT I HAVE GOING ON IN MY BODY”; DIFFERENTLY THE SYMPTOMS MANIFEST BASED ON GENETICS”***]. This understanding, from the patient perspective, can serve as complementary knowledge to inform care planning in addition to biological or pathophysiological knowledge (Kim, 2015). To date, no qualitative studies have explored the experiences of people living, specifically, with this subtype of long-COVID [***“WISH HEALTHCARE PROFESSIONALS [...] UNDERSTOOD THE LIVED REALITIES”***]. Similar to Albright et al.’s (2023) qualitative systematised review, the development of pulmonary sequelae was an unexpected occurrence for participants [***“DIDN’T EVEN COME TO MY THOUGHTS THAT MY LUNGS WERE REALLY DAMAGED”; “CAUGHT ME OFF GUARD”; COVID PNEUMONIA [...] NO ONE REALIZED I HAD”***]. Diagnoses were rarely provided through primary care routes [***“I DON’T HAVE A FAMILY DOCTOR”; “FAMILY DOCTOR CONFIRMED THAT SHE WOULD BUT DID NOT”; “DID NOT REFER ME TO A RESPIROLOGIST”; GENERAL PRACTITIONER [...] THAT’S ALL I EVER HEARD”***] and participants often underwent a complicated journey to diagnosis through emergency visits [***“WENT UNTREATED AT EMERGENCY VISITS”***], and extensive self-advocacy [***“TOOK SEVEREAL MONTHS TO GET [...] REFERRALS TO SPECIALISTS”; “I HAD TO ASK FOR A LUNG SPECIALIST”; “I HAD TO ASK FOR PHYSIOTHERPAY”; “I HAD TO PURSUE IT”; “CONSTANT EFFORT [...] FIND SOMEONE”***]. Interestingly, participants who were also part of large clinical trials experienced a smoother transition to diagnosis [***“RESEARCH CASE”; “CANCOV RESEARCH [...] IT WAS THE DOCTOR THERE [...] XRAY”***]. Similarly, participants with

pre-existing relationships with specialist teams were able to reach diagnosis, but this remained unexpected and was often achieved through routine follow-up [***“REALLY FORTUNATE [...] HAD PEOPLE THAT WERE ALREADY ESTABLISHED”; “FOUND IN ROUTINE CHECK”***]. Participants in this study describe various pathophysiological mechanisms contributing to their pulmonary sequelae, such as obstructive disease [***HYPERINFLATION OF THE LUNGS”; “BRONCHIECTASIS IN THE LOWER LUNGS”; “MUCUS PLUGGING ALL THROUGH THE LUNGS”; “DIAGNOSED WITH ASTHMA”; “RECENTLY DIAGNOSED WITH [...] COPD”***], often with secondary infectious complications [***“I HAVE MAC (mycobacterium avium complex)”; ACTIVE INFECTION ON TOP OF [...] COLONIZATION OF PSEUDOMONAS”; “ACTUALLY ACTIVE INFECTION”; “LONG INFECTIONS THAT WILL NOT GO AWAY”***], hypercoagulability [***“BLOOD CLOTS IN MY LUNGS”***], restrictive disease [***“PULMONARY FIBROSIS IN ALL LOBES OF THE LUNGS”; SCAR TISSUE THE REMAINING OF MY LIFE”; “SCARRING AND DAMAGE”***], and non-specific reductions in pulmonary function [***“LUNG CAPACITY”; “TESTS ARE INCONCLUSIVE”; PULMONARY FUNCTION TEST WAS DOWN TO 67%”; “SATURATION WAS 84”; “LUNG FUNCTION IS AT 69%”***]. Participants expressed that nuance is an important factor to understand the subjective experience of pulmonary sequelae [***“DETAILS AND INTRICASES I FEEL IS VERY IMPORTANT; “NEED TO KNOW HOW IMPORTANT [...] TO BE ABLE TO BREATHE”***]. Symptomatically, these pulmonary complications resulted in dyspnea for all participants regardless of reported biomarker data [***“SHORTNESS OF BREATH RIGHT AWAY”; “BREATHING PROBLEMS SINCE”; “GET WINDED SO QUICKLY”; PRESSURE ON CHEST, STRUGGLE TO BREATHE, WINDED EASILY”; “MORE AWARE OF BREATHING ESPECIALLY AT REST”; “BREATHING WAS EXTREMELY LABOURED”***]. Beyond the shared experience of dyspnea, additional pulmonary symptoms and treatment responses were reported by participants with specific reported complications. Those living primarily with obstructive disease with or without secondary infectious complications report difficulties with coughing and impaired airway clearance [***“COUGHING... I CAN’T STOP”; “COUGH IMPACTS MY SLEEP”; “DIFFICULTY BREATHING AND A BAD COUGH”; “COUGHING CONSTANTLY”; “COUGHING CONTINUES ALL DAY”; “MUCUS PLUGGING ALL THROUGH THE LUNGS”***]. Participants were often prescribed inhaled therapies such as corticosteroids or

PULMONARY SEQUELAE OF COVID-19

bronchodilators [***“TWO INHALERS THAT I USE NOW”; “I DO HAVE A PUFFER”; “NEBULIZE [...] PART OF THE DAILY ROUTINE”; “I TAKE SYMBICORT 200 4X DAILY”***], which was perceived as beneficial and was a significant part of self-health management [***“DIDN’T REALIZE HOW MUCH THE VENTOLIN HELPED”; “INHALERS HELPED ME A LOT”; “WOULDN’T BE ABLE TO DO IT WITHOUT MY INHALERS”; “WENT WITHOUT ALBUTEROL [...] SHORTAGE [...] CLEARLY HAS AN IMPACT”***]. When secondary bacterial infections were reported, bacterial species with serious health implications, including pseudomonas and MAC (mycobacterium avium complex) [***“I HAVE MAC (mycobacterium avium complex); ACTIVE INFECTION ON TOP OF [...] COLONIZATION OF PSEUDOMONAS”***] were reported as a significant stressor on overall health [***“CUMULATIVE EFFECTS OF THESE INFECTIONS”***], which required long-term antibiotics [***“12-18 MONTHS OF 3 ANTIBIOTICS”; ON ANTIBIOTICS FOR OVER 3 STRAIGHT MONTHS, SOMETIMES 2-3 AT A TIME”***]. In contrast, participants living primarily with restrictive disease experience changes to overall pulmonary compliance [***“WILL NOT EXPAND”; “ALL UPPER LUNG”; “IT’S LIKE BROKEN GLASS IN YOUR LUNGS”***]. Similar to those with obstructive disease, participant’s living mainly with restrictive disease were often prescribed inhaled therapeutics but without any benefit [***“PUFFERS, NO CHANGE WHATSOEVER”; DIFFERENT PUFFERS [...] WASN’T REALLY WORKING”***]. All participants with reported restrictive disease used supplemental oxygen therapy either currently or previously [***“ANY TYPE OF ACTIVITY I’VE GOT TO HAVE THE OXYGEN”; “OXYGEN FOR PROBABLY A MONTH”; “USED OXYGEN AT NIGHT [...] AND PHYSICAL ACTIVITY”***].

Appendix I: Distress Protocol

The researcher will intervene if the participant is exhibiting:

- *Discomfort or anxiety*, to ask if they would like a break and/or end the interview.
- *Distress*: the participant will be asked whether they want the interview to conclude and if they want the researcher to contact a family member or friend. The participant may then choose to continue or end the session.
- *Severe distress*: the researcher will stay on the line with the participant until they are composed and calm and offer to contact a friend or family member. The participant may then choose to continue the interview another day or end participation.

The researcher will:

- Request permission to contact them later in the day or the next day to confirm they are no longer stressed/distressed.
- Provide information for a crisis help line upon request.

Source: Dempsey, L., Dowling, M., Larkin, P., & Murphy, K. (2016). Sensitive interviewing in qualitative research. *Research in nursing & health*, 39(6), 480-490.

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Appendix J: Athabasca University Research Ethics Approval



CERTIFICATION OF ETHICAL APPROVAL

The Athabasca University Research Ethics Board (REB) has reviewed and approved the research project noted below. The REB is constituted and operates in accordance with the current version of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) and Athabasca University Policy and Procedures.

Ethics File No.: 25083

Principal Investigator:

Mr. Cameron Albright, Graduate Student
Faculty of Health Disciplines\Master of Nursing

Supervisor/Project Team:

Dr. Gwendolyn Rempel (Co-Supervisor)
Dr. Jacqueline Limoges (Co-Supervisor)

Project Title:

TERTIARY NURSING CARE FOR PEOPLE WITH PULMONARY SEQUELAE OF COVID-19: AN INTERPRETIVE DESCRIPTION STUDY

Effective Date: January 20, 2023

Expiry Date: January 19, 2024

Restrictions:

Any modification/amendment to the approved research must be submitted to the AUREB for approval prior to proceeding.

Any adverse event or incidental findings must be reported to the AUREB as soon as possible, for review.

Ethical approval is valid *for a period of one year*. An annual request for renewal must be submitted and approved by the above expiry date if a project is ongoing beyond one year.

An Ethics Final Report must be submitted when the research is complete (*i.e. all participant contact and data collection is concluded, no follow-up with participants is anticipated and findings have been made available/provided to participants (if applicable)*) or the research is terminated.

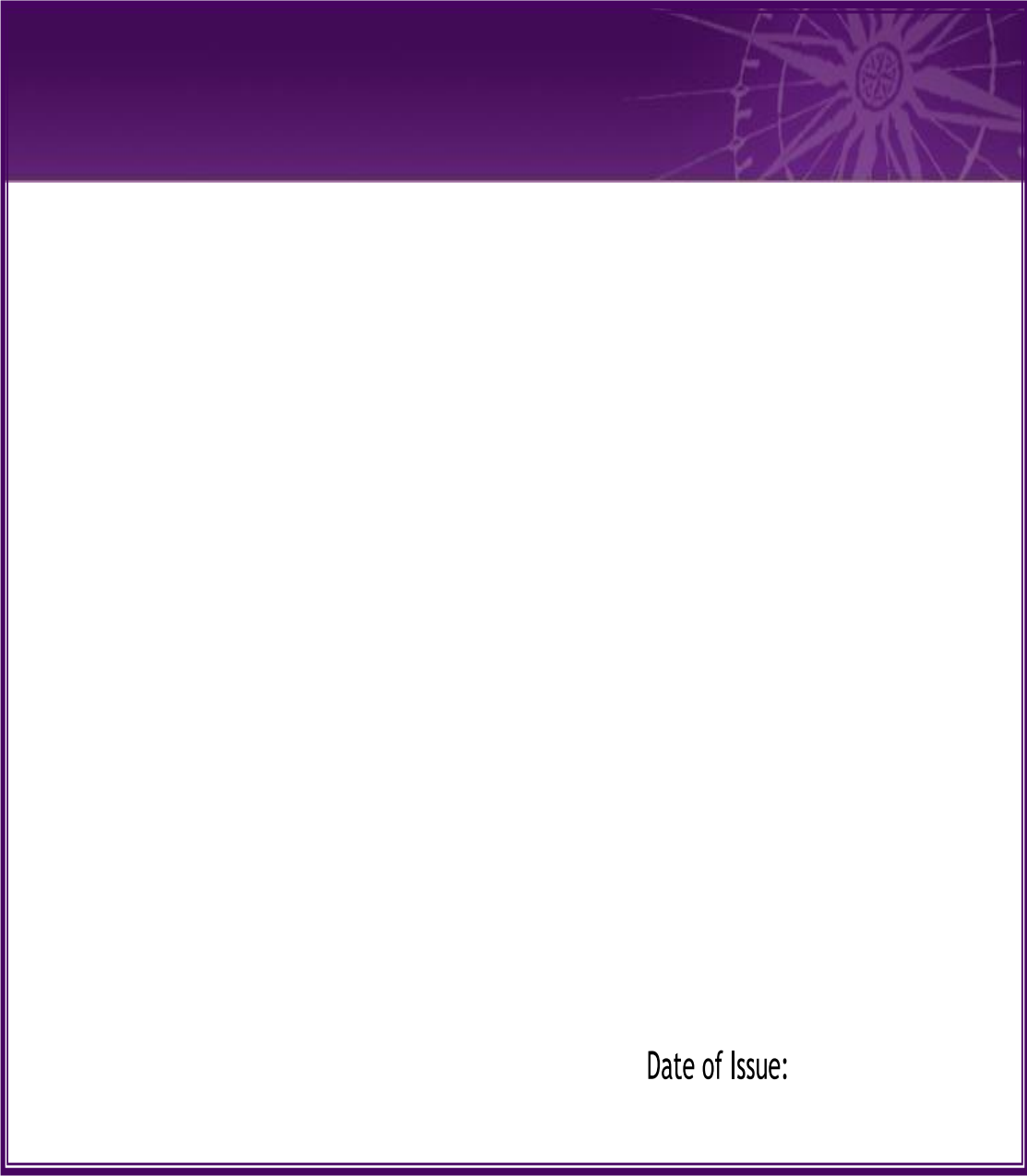
Approved by:

Date: January 20, 2023

Barbara Wilson-Keates, Chair
Athabasca University Research Ethics Board

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Appendix K: TCPS 2: CORE Certificate



Date of Issue: