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Clinician perspectives on Long-COVID physical rehabilitation: challenges, uncertainty, and semantics

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ABSTRACT

Purpose: To understand the perspectives of clinicians who provided rehabilitation services to people with Long-COVID or referred people to such services.

Methods: Clinicians involved with Long-COVID rehabilitation were recruited via email and interviewed. Recruitment continued until thematic saturation on physical rehabilitation approaches was reached. Semi-structured interviews were recorded, deidentified, and transcribed. Reflexive thematic analysis was used to develop themes from codes.

Results: Twenty-one clinicians were interviewed about their perceptions of Long-COVID rehabilitation. Clinicians were physiotherapists, exercise physiologists, clinical psychologists, respiratory physicians, rehabilitation physicians, an infectious disease physician, and a general practitioner. Four overarching themes were identified. (1) "Long-COVID is hard to characterise," including Subtheme 1.1 "Naming Long-COVID: opinions and impacts of differing terminology"; and 1.2 "Framing Long-COVID: one syndrome, experienced as many." (2) "Challenges of diagnosis in a novel condition." (3) "Management of a novel condition – Who knows what to do?" (4) "Exercise therapy is complex," including Subtheme 4.1 "Graded exercise therapy – semantic discordance despite alignment in approach" and 4.2 "Clinicians question public opposition to exercise."

Conclusion: Clinicians described Long-COVID as a heterogeneous condition which challenges traditional rehabilitation frameworks. This study highlights how uncertainty with rehabilitation methods leads to fragmented approaches to rehabilitation and inconsistencies in care.

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► IMPLICATIONS FOR REHABILITATION

- Long-COVID rehabilitation should be framed around a heterogeneous and largely "invisible" condition where validation of symptoms and careful assessment is prioritised.
- Where appropriate, exercise should be prescribed as highly individualised, symptom-titrated physical activity rather than rigid, pre-set incremental exercise programmes regardless of terminology employed.
- Discrepancies in terminology can undermine engagement; clinicians should aim for consistent and patient-friendly language (typically Long-COVID) while still aligning with formal terminology.
- Knowledge gaps and variable beliefs about models of care contribute to inconsistencies in patient management.

Introduction

On May 5th, 2023, the World Health Organisation (WHO) declared an end to COVID-19 as a global health emergency [1]. Large-scale coordinated efforts to reduce the spread of COVID through vaccination were influential in achieving this positive milestone [2], however, the effects of persisting COVID-related

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sequelae, colloquially termed “Long-COVID,” are widespread and responsible for significant global morbidity. Long-COVID is defined by the WHO as the continuation or development of new symptoms three months following an initial COVID infection with symptoms lasting for at least two months with no other explanation [3]. The National Academies of Science, Engineering, and Mathematics (NASEM) definition includes those who experience an exacerbation of their existing health condition as also meeting the criteria for Long-COVID [4]. The exact mechanism of Long-COVID is unknown, yet several have been hypothesised such as immune dysregulation, microbiota disruption, autoimmunity, clotting and endothelial abnormality, and dysfunctional neurological signalling [5]. Long-COVID is therefore a diagnosis of exclusion, often requiring numerous medical investigations which can be costly and time-consuming for patients [6].

People with Long-COVID often report their condition is not being taken seriously when attempting to access healthcare [7]. This could be a result of “Long-COVID” as a term originating on social media from those with lived experience as opposed to through traditional medical channels [8], or due to the often-negative test results (i.e., no abnormality detected) from health investigations [9]. Regardless, there is a long history of those with “invisible illnesses” (i.e., conditions without outwardly visible signs) receiving poor support and late or minimal recognition from healthcare systems and society, often due to ambiguity in the mechanism or measurability of symptoms [10]. This discrimination, sometimes borne through sexism or ableism, can leave sufferers feeling dismissed due to medical scepticism, with symptoms inappropriately attributed primarily to psychological causes.

Given the recency of Long-COVID, there is inadequate evidence to guide best practice in rehabilitation, and initially clinicians relied on expert advice through well-regarded health organisations [11,12]. There has existed and persists a concern over the safety of some rehabilitation interventions being provided, namely, of exercise interventions for people exhibiting post-exertional malaise (PEM) or post-exertional symptoms exacerbation (PESE) [12]. This may stem from controversies surrounding the use of graded exercise therapy in people with myalgic encephalitis/chronic fatigue syndrome (ME/CFS) [13–15] given the similar symptom profile with Long-COVID [16]. Proponents of graded exercise therapy in ME/CFS have suggested that carefully supervised activity may help to reduce deconditioning [17]. Critics of graded exercise therapy highlight the lived experience of those with ME/CFS demonstrating lack of benefit and that the studies that support graded exercise therapy are methodologically weak [14,18].

Noting these complexities that surround Long-COVID and the provision of effective rehabilitation services, an understanding of the perspectives of clinicians who provide or refer to rehabilitation services could provide important insights into the delivery of patient-centred care. The aim of this study was to understand the perspectives of clinicians who provided or referred people with Long-COVID to rehabilitation services.

Methods

Study design

A qualitative study that adopted a broad interpretivist approach and conducted reflexive thematic analysis using semi-structured interviews to explore the perspectives of clinicians. The study received ethical approval from the Sydney Local Health District (SLHD) Human Research and Ethics Committee (Protocol No X23-0215 & 2023/ETH01265). All clinicians who participated in the study provided informed written consent prior to undertaking an interview. This study was funded by an Allied Health Research Grant through the local publicly funded hospital and used the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist to ensure quality and transparent reporting.

Participants and recruitment

Participants included clinicians who provided outpatient rehabilitation for Long-COVID or medical practitioners who referred people with Long-COVID to rehabilitation. Researchers used existing networks to identify Australian-based clinicians who had provided such services within the prior 12 months. To recruit

participants, an invitation email approved by the ethics committee was sent to clinicians known to either refer to or provide rehabilitation for people with Long-COVID, with a maximum of one reminder, in order to avoid coercion. The email was sent by a junior team member unknown to the majority of invitees. Recruitment continued until thematic saturation of physical rehabilitation approaches was achieved, which was decided through iterative discussion by the interviewer (JR) and senior researcher (JA) and confirmed by the wider research team as the interviews progressed. The sample consisted of seven physiotherapists, five exercise physiologists, two clinical psychologists, three respiratory physicians, two rehabilitation physicians, an infectious disease physician, and a general practitioner. Three respiratory physicians and a general practitioner were those who referred to rehabilitation whereas the other clinicians were those who were involved with rehabilitation programs.

Semi-structured interviews

Interviews were led by a doctoral candidate (JR) with previous experience in qualitative research. The research team developed the semi-structured interview questions collaboratively based on their clinical and research experiences. Between them, these researchers had a variety of previous experiences working with people with Long-COVID, both in clinical practice and research. Semi-structured interview questions were open-ended and utilised further probing questions to more deeply understand the perspectives of clinicians ([Supplementary Table S1](#)). The interview questions were re-assessed collaboratively by the research team after the first few interviews and were considered appropriate. Interviews were audio recorded using a videoconferencing software, de-identified prior to transcription, and transcribed for the purpose of qualitative analysis. A transcription service was used to transcribe verbatim the audio recordings of clinician interviews. A researcher checked the transcripts for accuracy (JR). Participants were informed the study was being conducted as part of a doctoral thesis. Field notes were not collected.

Analysis

Our study is best described by its analytic approach rather than alignment with a specific traditional qualitative methodology (e.g., phenomenology or grounded theory). From an epistemological standpoint, we adopted a subjective interpretivist approach and conducted reflexive thematic analysis using semi-structured interviews. This inductive approach allowed themes to emerge organically from the data, without imposing predetermined theoretical frameworks, enabling theory to be developed based solely on participant accounts. Interview transcripts were coded by a researcher (JR) using NVivo 14 (QSR International, Melbourne, Vic., Australia). Early in the coding of interviews, codes were checked by a senior researcher (JA) and any differences in interpretation discussed and resolved to ensure codes were developed rigorously, were accurate, and were insightful in characterising the data. Using thematic analysis [19–22] the researchers identified key themes from clinician interviews regarding the provision of rehabilitation for people with Long-COVID. A researcher (JR) presented the codes, identified quotes, and early constructed themes to the wider team for discussion and finalisation. Multiple researchers (JR, JM, LS, LLT, AB, JA) then reviewed the data and themes, held discussions to review, amend, and further develop the themes. Final themes were agreed by all researchers based on the coding of the transcripts.

The research team consisted of clinicians with experience of providing rehabilitation services for people following COVID infection (JR, LS, LLT), researchers who have previously published on rehabilitation for people with Long-COVID (JR, LS, LLT, AB, JA), researchers with experience in qualitative research methods (JR, JM, LS, LLT, JA), and researchers who convene a collaboration of clinicians, researchers, and consumers (Long-COVID Australia Collaboration; AB, JA).

In terms of positionality, investigators acknowledge that their previous experiences in providing healthcare services for, and conducting research with, people who experience Long-COVID could influence study findings. Between them, these researchers had a variety of previous experiences working with people with Long-COVID, both in clinical practice and research. They acknowledged the impact their professional backgrounds in physiotherapy (JR, LS, LLT, JA), clinical psychology (AB), and social anthropology (JM) would have on analysis and interpretation. For example, physiotherapists tended to focus on aspects of physical rehabilitation and how they were perceived while those with a background in

psychology and anthropology brought attention to cultural context, navigating the health system, and how opinions align with alternate health contexts. This study demonstrates trustworthiness through transparent coding procedures and collaborative theme development involving multiple researchers [23]. Credibility is further strengthened by reflexive acknowledgment of researcher positionality and iterative discussions to resolve differences in interpretation.

Results

A total of 21 health professionals (11 female, 52%) were interviewed between October and December 2023. Interviews were an average of 30 minutes (range 17 to 43 minutes) and were conducted via video-conference. Participants recruited were from Sydney and Melbourne in Australia.

Despite the common use of telehealth, there were differences in the geographical areas to which services were provided, typically due to organisational factors. Private clinics generally provided services over greater geographical areas while public hospital-based services were restrained within local health districts. Most clinicians interviewed were from public hospital settings (n=15, 71%) and these settings tended to have greater diversity of health professions involved in the management of Long-COVID.

Four key themes and four subthemes were identified through the interviews. The key themes and associated sub-themes are presented below with illustrative quotes. Further illustrative quotes for each theme are reported in the supplementary materials. ([Supplementary Table S2](#)).

Theme 1: Long-COVID is hard to characterise

Clinicians reflected on diversity and ambiguity in the naming conventions for Long-COVID and that the variety of presenting symptoms led to Long-COVID being experienced in different ways by patients.

Subtheme 1.1 – Naming Long-COVID: opinions and impacts of differing terminology

Interviewed clinicians were reminded of several terms used synonymously with Long-COVID, including Post-COVID Condition, Post-acute Sequelae of COVID (PASC), and Post-COVID Syndrome (PCS), in order to gain their opinions on the differing terminology use. Some clinicians suggested that the term used should be different dependant on context; based on whether being used in research or professional settings versus in a patient-facing clinical practice setting.

It depends on who it's focused on. Whether you're more kind of talking from a patient's perspective or a clinician's. – Participant 13 (Physiotherapist, female)

Almost all clinicians held the view that “Long-COVID” was the most ideal term, typically because clinicians understood “Long-COVID” as the term that made most sense to patients and to the public. Some quite strongly favoured the use of “Long-COVID” as the preferred term in a public setting, with terms like “alienate” and “intimidating” used when describing alternate terms such as post-acute sequelae of COVID. Others were less bothered by terminology, merely suggesting Long-COVID may be most appropriate.

Well, we use the WHO definition, which is post-acute sequelae of COVID (Long-COVID). If you use PASC, then you alienate the public. If you use Long-COVID, the public knows what you're talking about. – Participant 21 (Rehabilitation Physician, male)

We call our clinic the Long-COVID clinic. But, I mean, the official term is PACS, Post-acute COVID sequelae. [...] Long-COVID is what people understand, so that's the term we use. – Participant 17 (Respiratory Physician, male)

Some expressed the view terminology in all contexts should be uniform, and that different terms brought about confusion for both patients and clinicians.

I think all the different terms - it probably gets confusing for the patients to be honest. There's so many different terms it can be known as, I think trying to find one phrase, or one way of defining it, would be beneficial for patients. – Participant 6 (Exercise Physiologist, female)

Rather than holding a preference for the term “Long-COVID,” others viewed the inclusion of the word “sequelae” in terminology (alluding to the term “Post-acute Sequelae of COVID”) was the main issue i.e., that the exclusion of health jargon.

I think probably post-COVID syndrome, or Long-COVID, are probably the more simpler ways than post-sequelae, people are like, ‘what the hell is that?’ – Participant 6 (Exercise Physiologist, female)

One clinician was actively against the use of the patient-coined term “Long-COVID” due to concerns that this may lead to misdiagnosis if other medical conditions had not be ruled out.

I think one of the problems with using the term Long-COVID is that people will come to the clinic and say, I’ve got Long-COVID ... - whereas in fact they might have something else. So if we did actually use a different term to diagnose the condition, for example, post-acute SARS-CoV-2 syndrome or something, that would be maybe more accurate, if that makes sense? – Participant 15 (Rehabilitation Physician, female)

One clinician recalled a personal experience in publishing research where terminology was challenged.

Well, I wrote a paper and wrote Long-COVID all the way through it and then I had to change it to Post-COVID Condition in order to get it published. – Participant 8 (Physiotherapist, female)

Three clinicians likened Long-COVID to post-acute infective syndromes (PAIS) also known as post-viral syndromes, i.e., conditions where there is a symptom profile centred around chronic fatigue that occurs in a small percentage of people following a viral infection such as Epstein Barr or Ross River virus. They expressed opinions that Long-COVID should be identified as another PAIS, but caused from a different viral pathogen i.e., SARS-CoV-2.

.....largely what’s been called Long-COVID falls under that banner [i.e PAIS]. [...] this is not a criticism, but the field, both in clinical practice and in research, has worked from an assumption that ongoing symptoms after COVID are new and special and never been seen or heard of before, when in fact, post-infective sequelae that look and feel and probably have the same disease process are very common after a whole range of infectious diseases. - Participant 11 (Infectious Disease Physician, male)

I think there still needs to be some clarification as to, is this disease something that’s specific to COVID only or is this very similar and overlapped with other general post-viral conditions, which seem to harbour very similar symptom profiles as well. The fatigue, the brain fog and things like that. It’d be very interesting to see the research on that and see how that develops. – Participant 9 (Clinical Psychologist, male)

One late-career clinician-researcher with life-long experience in treating PAIS, who felt strongly that Long-COVID is another form of PAIS in most people, described the similar post-acute symptomology that results despite diversity in the presentation of the acute illness.

Post-infective sequelae are very similar to each other with minor variations, lots of pain after Ross River virus, lots of sore throat after EBV, lots of sweats and headaches after Q fever. From my point of view loss of taste or smell or the complaint of loss or taste or smell, or dyspnoea after COVID is a variation on a theme. [...] From my point of view, that is a minor variation on the fundamental principle that all other post-infective sequelae fall under the same banner. – Participant 11 (Infectious Disease Physician, male)

Subtheme 1.2: Framing Long-COVID: one syndrome, experienced as many

All clinicians interviewed empathised with the plight of those experiencing ongoing COVID sequelae and shared an interest in providing rehabilitation services. Whether working with people with invisible illnesses for many years or working just with people with Long-COVID since the start of the pandemic, all clinicians spoke of Long-COVID as a legitimate condition that warrants health care services, regardless of the extent of services they viewed as appropriate.

We’ve been dealing with these sorts of syndromes for decades and decades and decades with virtually no support all of the time. The people with chronic fatigue and fibromyalgia syndromes and whatever, they’ve still got the same issues with little support. – Participant 11 (Infectious Disease Physician, male)

Despite the inclusive WHO definition for Long-COVID, many clinicians, especially those practicing medicine for patients seeking management of their symptoms, believed diagnosing “Long-COVID” as a

standalone condition is less than ideal. This was due to sentiment that it may be over-inclusive and should be further differentiated for optimal management. One clinician even commented “it’s a dog’s breakfast really, completely and utterly” when speaking to the diversity of “Long-COVID” presentations.

I think as a whole we should try not to be using broad descriptors that don’t actually seek to understand what the contributing factors are. – Participant 19 (Respiratory Physician, female)

No one quite knows what it is [Long-COVID], in both clinical practice and in research, [that] they’re dealing with. I don’t mean that in relation to what’s the mechanism of disease, but things are being lumped together under the banner of each of those terms you made, inappropriately with very heterogeneous disease processes being branded in the same way. – Participant 11 (Infectious Disease Physician, male)

So everyone saw the doctor first, which we all thought was important because Long-COVID is so undifferentiated, need to actually examine people and so forth. – Participant 15 (Rehabilitation Physician, female)

One clinician expressed that in the future Long-COVID may be divided into different conditions or sub-phenotypes.

I wonder if in 10 years whether we are going to have separated into five or six different conditions. It seems like it’s - of the patients you see with the syndrome, they’re so varied and there must be some different sub-phenotypes in there. – Participant 8 (Physiotherapist, female)

Perceptions of illness and symptoms involve a complex interplay of physiological and psychological components for many different health conditions, especially PAIS. Clinicians believed that the manifestation of COVID-sequelae in those with Long-COVID stemmed from an underlying physiological mechanism which contributed to symptoms, but often suspected symptoms were exacerbated by psychological factors, making references to “anxiety,” “trauma,” “mental health,” “burn out,” “not coping,” “depression,” and “pre-existing health concerns.”

Then there’s psychological overlay on a lot of those symptoms and there was a lot of people who went through a lot of trauma, in and around that time, people with pre-existing significant mental health conditions, or trivial mental health conditions, but overlaid with trauma. So I think all of it [their symptoms] relates to COVID, to varying degrees, but for varying reasons. – Participant 19 (Respiratory Physician, female)

I have seen quite a lot of patients that are really anxious. Whether the anxiety is also driven to their current symptoms, it’s really harder to say. But the patient presented that’s what they had after the COVID, so I have to believe in some way. – Participant 12 (Physiotherapist, female)

Many clinicians held the belief that pre-existing stress or other negative psychological symptoms, in some, exacerbated Long-COVID symptoms. One clinician suggested “care must be taken in terms of accounting for what pre-existing medical and mental health conditions already existed.” This was sometimes viewed as leading to symptoms that were more severe than would otherwise be expected.

So, if someone already has a pre-existing anxiety for example, it’s likely that COVID and the resulting Long-COVID symptoms, if that’s what’s happened, has exacerbated what was already a pre-existing anxiety condition, perhaps, rather than saying that Long-COVID has caused anxiety specifically. [...] the more that that has shown up in the history, the more vulnerable I think that the person is towards developing Long-COVID and the really detrimental impacts of Long-COVID as well. – Participant 9 (Clinical Psychologist, male)

Holding views of mixed psychological and pathophysiological origins for illness did not typically imply scepticism for the legitimacy of a patient’s condition. At times, clinicians interviewed (all of whom were active in supporting those with Long-COVID) showed frustration with the negative attitudes held by some of their colleagues towards the condition. They expressed disappointment when other health professionals denied Long-COVID as a medical condition or when they were disinterested in providing healthcare services for those attempting to access care.

Yeah, I still have colleagues – we still have people make dumb a** comments about, ‘this is all fairy dust, it doesn’t actually exist. Why have we even got it on our agenda? Why aren’t we talking about real, proper disease or real evidence-based stuff’ - really sad to hear. – Participant 18 (General Practitioner, male)

I think that’s - well, smacks of discrimination and ignorance [referring to medical practitioners avoiding Long-COVID patients]. [...] It’s a new disease and everyone wants it to be over, but it’s not. It’s got a chronic phase and people have to learn about it. – Participant 21 (Rehabilitation Physician, male)

Occasionally, some of this reported reluctance of health professionals to treat Long-COVID patients came about from diagnostic challenges including inconclusive testing, which is explored in the following theme. In situations where tests did come back negative, one clinician recalled how her patient was reportedly abandoned by their treating doctor.

The person that I'm seeing at the moment, for example, he has gone through all the tests, all the scans, all shows normal, but I believe his feeling is real. Yeah, so in terms of diagnosis, all the doctors are saying that he's fine, he's fine, he shouldn't feel that. – Participant 2 (Physiotherapist, female)

Theme 2: challenges of diagnosis in a novel condition

Clinicians acknowledged Long-COVID as a diagnosis of exclusion. This meant undertaking investigations to identify other potential causes for a patient's reported symptoms. Of the physicians interviewed who diagnose Long-COVID, there were sometimes opposing ideas as to the benefit of this process of exclusion. Some found it to be necessary in arriving at a Long-COVID diagnosis.

If we're going to apply one of these brands of Long-COVID or PCC or PASC, then the symptom set that's being complained of should be medically unexplained. If you're going to get to the point of saying it's medically unexplained, you have to have done a structured medical assessment both for physical health issues and for mental health issues that might explain the symptom set, and that includes some investigations to make sure you've crossed all the T's and dotted the I's. – Participant 11 (Infectious Disease Physician, male)

Others felt Long-COVID patients were “quite resource intensive” for clinicians such as general practitioners and that numerous investigations into all a patient's symptoms, of which there are commonly multiple, unnecessarily pathologised their unexplained symptoms.

Some of that is actually going through a whole lot of investigations to rule out problems and it does put them into a system of sort of medicalising and pathologising a lot of issues that don't require those sort of investigations. – Participant 19 (Respiratory Physician, female)

Others sat in the middle of these opposing perspectives on the importance of exhaustive investigations, suggesting a core set of tests may be appropriate, but not continuing with an extensive list as a part of a routine evaluation.

We [speaking of multidisciplinary clinic] probably take a more holistic view of things [...] make sure everyone has had blood tests and that all other sorts of causes have been ruled out, at least most of the broad causes. Then, yeah, kind of seeing what happens from there, but not then pursuing further sort of investigations, like brain MRIs and all of the other stuff. – Participant 4 (Exercise Physiologist, male)

Two physiotherapists noted some of the difficulties that referrers face in private clinic settings, given the resource intensiveness of investigations. They reflected how this system pressure may have led to quick Long-COVID diagnoses.

The GPs don't have the time for these – to actually be able to drill down to these patients. You've got a 10-minute GP appointment and most Long-COVID patients need to tell you more than that. – Participant 1 (Physiotherapist, female)

Conversely, other rehabilitation providers felt referrers were reluctant to provide a Long-COVID diagnosis, especially when referring to a specialised Long-COVID clinic.

There are a few that do state they have Long-COVID, but a lot of them, I'm finding now, especially the more, I guess, widely known our clinic becomes, it seems that they're just – it's coming through as a referral for ongoing symptoms after an infection. Rather than saying, yes, they have Long-COVID. – Participant 6 (Exercise Physiologist, female)

Occasionally, clinicians had patients who they believed to be misdiagnosed with Long-COVID. Following medical investigations, physicians occasionally stated symptoms reported by patients were better explained by an “alternate diagnosis.”

One of the issues is you've got to have had COVID. Some people don't know, and then we do tests and we find out maybe they haven't. Other times, it's people - a pre-existing condition that worsened by COVID but is not caused by COVID. – Participant 19 (Respiratory Physician, female)

Theme 3: management of a novel condition – who knows what to do?

Of the clinicians interviewed, there was a consensus that those providing services to people with Long-COVID lacked knowledge of how to offer optimal rehabilitation or management. This was established in two separate forms, (1) an individual clinician admitting to not knowing how to appropriately advise a patient or, (2) clinicians perceiving that other health professionals did not have adequate knowledge and skills to provide services based on an up-to-date understanding of Long-COVID management.

Those who felt they were ill-equipped to provide appropriate advice sometimes struggled to manage patient expectations about their participation in rehabilitation services.

I found that I cannot really give them a lot of reassurance because a lot of time I will just say I don't really know. There are many situations that I don't know why they present this way. [...] I guess, yeah, number one is education, we do not have enough knowledge to deal with these people and also expectation. I found that people expect us to do something with them but then sometimes we just can't. – Participant 2 (Physiotherapist, female)

Those who reflected on the uncertainty that surrounds providing effective rehabilitation services related their experience to limits in available research using terms and phrases such as "evidence," "guidelines," "literature," and "knowledge and practice gap" to describe the ceiling in what they can provide.

I think that we should be honest as clinicians saying we don't really know what's going to set you off. We don't know that this is definitively going to make you better, the evidence is still very fuzzy. We can't say that to them, but there are blurry guidelines for what's going to work. – Participant 1 (Physiotherapist, female)

I think the lack of consensus, and I guess the commentary in the literature on what is an effective treatment for Long-COVID, or Chronic Fatigue, is a big challenge for people to sort of understand what the right thing is to do. – Participant 4 (Exercise Physiologist, male)

Some clinicians spoke of how uncertainty and ambiguity in what constitutes best-practice rehabilitation services had led to disparate advice to patients as well as non-uniform and fragmented care. One clinician noted "Then you have - for patients - going to different clinicians and getting different answers." – Participant 8 (Physiotherapist, female)

Without being critical but reflecting the uncertainties around what is Long-COVID, there's a bunch of clinics that emerged out of either the respiratory medicine rehab space, sometimes the neuro rehab space, sometimes the rheumatology rehab space, and all with somewhat different paradigms of what they think they were dealing with and trying to do. [...] Both the patients and the practitioners were struggling to understand what the hell they're supposed to do, not always with good outcomes. – Participant 11 (Infectious Disease Physician, male)

At times, those referrers expressed concerns about the services provided by allied health professionals. Whilst many acknowledged limitations in providing evidence-based services given knowledge gaps in research, some were of the opinion that a lack of clinician knowledge led to poor patient outcomes.

What I would say about rehab - and what I've heard many times from patients, both in the clinic and privately - is that they might have seen an exercise physiologist or they might have seen a physio without experience in Long-COVID, and the exercise physiologist thought the physio would give them a bunch of exercises and do it in a gym just like any other person. – Participant 17 (Respiratory Physician, male)

Not to be critical, but most clin psychs [clinical psychologists] don't understand fatigue, they think of it as some kind of a depression equivalent, which is not good. Most exercise physiologists or physios don't understand the paradigm of symptom limited constraints on how much you do as opposed to the push through kind of notion. – Participant 11 (Infectious Disease Physician, male)

I think a bit of in-servicing and upskilling is always beneficial. If the primary health networks and stuff provide training for different allied health professionals in different forms of Long-COVID rehab it'd be really, really good. – Participant 18 (General Practitioner, male)

A wide range of challenges were identified when providing rehabilitation services for people with Long-COVID. The most identified challenge was the diversity of sequelae that patients presented with, whether diverse within a single patient or between patients (“no two long COVID patients are the same” – Participant (P)16). Other commonly identified challenges were the cost involved with services (“It’s very expensive outside of public hospitals” – P21), limitations in participation due to post-exertional malaise or other symptoms (“the problem of post-exertional flare of symptoms is common in Long COVID... we need to modify our [exercise] prescription” – P17), lack of available services, lack of improvement following participation in rehabilitation, and patient work commitments. Conversely, clinicians were able to identify several facilitators for providing rehabilitation services. Common facilitators included the use of telehealth (“The fact we’re virtual has helped, because they can do it from the comfort of their own home” – P6), individualised rehabilitation programs, supportive environments that validated patient symptoms, and the use of evidence-based practice in rehabilitation models of care.

Theme 4: exercise as therapy is complex

Clinicians interviewed spoke of a diverse number of interventions used to target Long-COVID. Common interventions included pacing and energy conservation strategies, exercise and physical activity-based interventions (whether labelled as graded exercise therapy or not), and psychological support. Less common interventions included breathing retraining for people believed to have dysfunctional breathing, inspiratory muscle training to address dyspnoea, motivational interviewing, and autonomic retraining. Parallel to providing these interventions, most clinicians spoke of the importance of validation of the patient’s condition and providing reassurance when delivering rehabilitation services. Other clinicians spoke of the benefits of relaxation techniques, self-management strategies, coping strategies, and behaviour change interventions. There were no major conflicting opinions uncovered on the usefulness of common interventions employed, except for exercise. Opinions surrounding the use of exercise, specifically the use of “graded exercise therapy,” were polarised within the sample of clinicians interviewed.

Sub-theme 4.1: graded exercise therapy: semantic discordance despite alignment in approach

Clinicians providing rehabilitation services for people with Long-COVID often had opposing opinions on the appropriateness of graded exercise therapy as a form of rehabilitation. Despite this, those with opposing views surrounding graded exercise often described a similar rehabilitation process of what they considered as optimal, signifying that much of the disagreement may stem from a difference in the interpretation of the term “graded exercise therapy” or more specifically “graded” itself.

Those who were opposed to graded exercise therapy on face-value held a view that there was a lack of a tailored approach, and that the term “graded” implied preordained intervals that increase in intensity regardless of a patient’s presentation.

We don’t use graded exercise programs or graded exercise therapy, because the notion of that is that there’s one size that fits all and you fit into a program and you just go from stage to stage -a bit like Lego blocks, right? But what we think is an individualised exercise - sorry, individualised activity and movement programs are what are required. [...] Graded exercise programs are prefabricated and preordained. - Participant 21 (Rehabilitation Physician, male)

Clinicians opposing the use of graded exercise therapy made an argument that a tailored and symptoms-titrated approach to physical activity was most appropriate and that “prefabricated,” “preordained,” or “progressive incremental exercise” at preset increments was inappropriate. Interestingly, clinicians who were in favour of graded exercise therapy held the same view. The difference was that those in favour of graded exercise felt that any exercise, or even any physical activity, that builds on what has been done previously (such as sitting up in bed if the person had not done so recently) would fall under the banner of graded exercise therapy. Regardless of clinician views on what constitutes graded exercise therapy, approaches to rehabilitation for those with Long-COVID appeared similar between all clinicians interviewed. Those in favour of graded exercise therapy often referred to contention surrounding the definition.

Early on, on some of the physiotherapy podcasts with say [names podcast host] and so forth, there was - I recall seeing things saying graded exercise is bad for you, you shouldn't be doing it, et cetera, et cetera. But in reality, everything's graded exercise really, isn't it? Like breathing exercises are still graded exercise, autonomic rehab is still graded. So I feel graded exercise is beneficial, but the term graded exercise means to some people that you're going to flog them and they're going to work really hard, and it totally is triggering to them [i.e., the patient reacts poorly to the idea]. - Participant 15 (Rehabilitation Physician, female)

Whether you call it exercise, or whether you call it grading, or whether you call it pacing is open for discussion. But the point is, it's some sort of physical prescribed activity plan that's medically supervised. I think [that] makes infinite sense. Anyone that says otherwise, I think, is not a physician, is not a researcher, and is not looking at the evidence. - Participant 17 (Respiratory Physician, male)

Clinician perceptions of how graded exercise therapy is defined appeared to play a role in their advocacy or objection towards its use. Some clinicians were more neutral in their stance and spoke of graded exercise as appropriate in certain conditions or with caveats, yet once again described a physical rehabilitation approach tailored to the specific presentation of the individual.

I think some people struggle to get past activity pacing, and I think it's very important that we don't get people to grade up their activity before they've started to pace well, and their symptoms are under control. So some people don't get to it, but I think it is appropriate for everyone. - Participant 4 (Exercise Physiologist, male)

Graded exercise is [beneficial], with the caveat that if they're having crashes after the graded exercise, you have to be prepared to just change the intensity of the exercise. - Participant 1 (Physiotherapist, female)

Semantic discordance about what constitutes graded exercise therapy yet similar approaches were seen in this group of clinicians, all of whom were experienced in managing individuals with Long-COVID. That is not to suggest that all clinicians are using exercise rehabilitation safely, titrated based on an individual's presentation. One referrer acknowledged that there are health professionals who do not prescribe exercise appropriately, recalling where rehabilitation providers prescribed inappropriately high intensities for people who exhibited fatigue.

There's been one or two instances where the patient felt the physio was pushing them too hard and then we just changed teams. - Participant 21 (Rehabilitation Physician, male)

Sub-theme 4.2: clinicians question public opposition to exercise

Whilst clinicians appeared to provide similar rehabilitation programs that were individualised and that prescribed using symptoms-titrated intensity, differences in their perception of the term "graded exercise therapy" led to divided opinions on the appropriateness of its use. Statements from clinicians in public forums about graded exercise therapy may have been misconstrued, potentially fuelling public opposition to any exercise or physical activity-based rehabilitation intervention. A few clinicians identified social media as a potential driver for such public opposition to graded exercise therapy, or by extension, any prescribed exercise or physical activity-based program. One clinician stated, "there's a whole political consumer lobby social media problem."

With the exercise, I think a lot [of] the very vocal Twitter groups they're saying, you definitely shouldn't exercise these people. But we found benefit in exercise that has been personalised to the patient. It's not just sticking one size fits all, and that we've checked their response and we're monitoring them. - Participant 13 (Physiotherapist, female)

You probably know this, but in the fatigue world, in the chronic fatigue syndrome or [CFS/ME] world, I flagged some of the patient consumer groups, especially in the UK, have developed a very polarised stance against graded exercise [...] that's just push the whole agenda off on a mistaken tangent. - Participant 11 (Infectious Disease Physician, male)

Clinicians described public sentiments to exercise using words and phrases such as "a bit of a bad word," "demonised," and "really scary." One exercise physiologist commented on difficulty engaging some patients due to resistance to the idea of exercise as a treatment.

There is a barrier in seeing an exercise physiologist, though, because of the term exercise, and how it's demonstrated, so that more severe people think, I can't get out of bed. How? There's no point seeing an exercise physiologist. - Participant 7, (Exercise Physiologist, male)

Many clinicians reflected on public-driven opposition to any intervention that involves exercise (including graded exercise) and the challenges to overcome such a viewpoint when providing rehabilitation services.

Because we did have people come into the clinic saying I heard someone on a podcast say, if a therapist, physiotherapist or EP says to you they're going to do graded exercise, run a mile because that is harmful. - Participant 15 (Rehabilitation Physician, female)

I don't know if you've come across this, I'm sure you have. But, when we initially were talking about rehab, there's a certain group of people that are very much against any physical sort of anything in Long-COVID, because of this idea of making things worse and extrapolation from some people with chronic fatigue that have these problems. - Participant 17 (Respiratory Physician, male).

Then we'll look at stabilising and then we talk about exercise, but we refer to it as sustainable movement because exercise is a bit of a bad word within – especially the ME/CFS populations, so it's got to be at a level that doesn't cause symptoms or limit other activities of daily living. - Participant 7 (Exercise Physiologist, male)

One clinician, who's stance was pro-graded exercise therapy (based on semantics rather than approach), captured their perception of the rationale behind public opposition to exercise.

In the clinic we advocate strongly for graded exercise, and we argue quite strongly against the polarised consumer-led bias that graded exercise is not appropriate. The reason for that is - this is a bit simplistic - but my sense is that provided it's prescribed carefully and appropriately, it's always an appropriate thing to do. You probably know this, but the backdrop to the concern you might call it, generally relates to the fact that if you over-prescribe an over ambitious exercise program, you will inevitably make symptoms worse. [...] Even in patients who are housebound or not much better than bedbound, you can always do a graded exercise program that says, walk to the kitchen or walk into the back garden or do a one-minute little stretching routine. Something that's incredibly safe. - Participant 11 (Infectious Disease Physician, male)

Discussion

The aim of this study was to understand the perspectives of clinicians who provided or referred people with Long-COVID to rehabilitation service, which has been achieved through the identification of four key themes and four subthemes. Theme 1 *Long-COVID is hard to characterise* demonstrates how clinicians may exhibit differing views on how we should name and frame Long-COVID. This theme includes Subtheme 1.1 *Naming Long-COVID: opinions and impacts of differing terminology* which explores the challenges surrounding terminology use; and Subtheme 1.2 *Framing Long-COVID: one syndrome, experienced as many* which investigates the diversity of Long-COVID presentations and associated implications for care. Theme 2 *Challenges of diagnosis in a novel condition* sheds light on divergent approaches to diagnosis, whether protocol or pragmatically driven. Theme 3 *Management of a novel condition – Who knows what to do?* highlights clinician uncertainty in providing rehabilitation and management services, whether due to limitations in understanding of what is known to be effective, or due to the perception that others did not possess adequate knowledge and skills to provide services based on an up-to-date understanding of Long-COVID management. Finally, Theme 4 *Exercise therapy is complex*, discusses the ongoing controversies that surround exercise as a treatment, including Subtheme 4.1: *Graded exercise therapy – semantic discordance despite alignment in approach*, which outlines how differing interpretation about what “graded exercise” means may be responsible for part of the contention surrounding its endorsement in Long-COVID populations as opposed to a difference in the rehabilitation approach itself; and Subtheme 4.2 *Clinicians question public opposition to exercise*, which explores how consumer-driven concerns for the use of exercise therapy through social media, perhaps originating from clinical disputes about the role of graded exercise therapy, has led to difficulties for clinicians to employ any exercise or physical activity-based approach, even in patients who may be suitable.

Characterising Long-COVID

Clinicians highlighted the confusion that surrounds the lack of uniform terminology in public discourse, mostly for patients seeking care, but also for themselves. “Long-COVID” or “long-haulers,” as a term, was originally coined by those with lived experience who united through social media [24]. An array of alternate medical terms have since been employed by different global organisations, including “Post-COVID condition (Long-COVID)” by the World Health Organisation [3], “Post-COVID Syndrome” by the National Institute of Health and Care Excellence (NICE) [25], and “Post-acute sequelae of COVID” by the US National Institutes of Health (NIH) and the Australian Department of Healthcare and Ageing [26]. These terms are mostly synonymous and used interchangeably, however, some differences stem from the timeline required from infection to diagnosis [27]. For example, NICE suggest the label of “Long-COVID” is applied for those exhibiting persistent symptoms from 4 weeks post infection as opposed to WHO which suggests 12 weeks post infection. The discordance in terminology between global organisations coupled with a reticence to use the patient-coined and preferred term “Long-COVID” may represent a case of epistemic injustice in medicine as knowledge is only validated when sourced through traditional scientific channels as opposed to lived experience [28]. Such discordance may lead to heterogeneous study populations all identified as “Long-COVID” and therefore create difficulty synthesising evidence.

Long-COVID is a multisystemic and diverse condition. There are over 200 symptoms reported [5] with over 50 as common [29]. Whilst there is a typical symptom profile centred around chronic fatigue [30], those with Long-COVID can present quite uniquely. Numerous clinicians commented on the diverse presentations of their patients and often viewed Long-COVID as undifferentiated with symptoms of “heterogeneous disease processes” being “lumped together” under the banner of Long-COVID. There was sentiment that “broad descriptors” do not allow for understanding of the contributing factors, which can be problematic for delivering and researching targeted interventions. Acknowledging such heterogeneity, efforts have been made to phenotype Long-COVID by evaluating symptoms clusters [31,32]. NICE acknowledge in their guidelines for managing the long-term effects of COVID that Long-COVID typically presents with “clusters of symptoms” which can affect “any system of the body” and have recommended further research into interventions to target identified symptom clusters [25]. However, symptom cluster identification has yet to translate into effective rehabilitation interventions.

Diagnosis of Long-COVID

Our study also found that physicians had mixed ideas on the utility of investigations to diagnose Long-COVID. Some believed it was necessary to confirm a diagnosis through extensive investigations to exclude differential causes for symptoms, while others felt it unnecessarily pathologised and medicalised an invisible illness. A recent qualitative study examining the perspectives of general practitioners and people with Long-COVID found that Scottish general practitioners also struggled with arriving at a diagnosis of Long-COVID, due to the lack of a definitive test and with minimal options for treatment following a diagnosis [33]. In this study, those with lived experience of Long-COVID could acknowledge diagnostic difficulties but often felt judged for reporting symptoms, as though they were a malingerer. Another qualitative study found that people with lived experience of Long-COVID held the opinion there was a reluctance among GPs to diagnose a patient with Long-COVID as this could mean burdening themselves with the need to provide ongoing care for a complex condition (of which there was limited understanding) [34]. Differences in opinion about the validity of a Long-COVID diagnosis may mean those with symptoms are unable to access care.

Managing a novel condition

Invisible illness is a term used to describe conditions that do not have outwardly visible signs.

Unlike a wound that bleeds or requires stitches, a mending limb that is encased in a cast, or malfunctioning legs that necessitate use of a wheelchair, the symptoms of invisible illnesses have no external evidence of suffering that elicit compassion. Instead, the patient often endures suspicion and withdrawal from others [35].

– Sick and Tired of Feeling Sick and Tired, P Donoghue & M Seigel

In situations where invisible illnesses additionally do not have objective measurable signs or conclusive diagnostic tests, further suspicion can arise from healthcare practitioners. The history of healthcare provision for those with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) provides an example of how medical scepticism over the legitimacy of symptoms has previously led to poor care [36]. Due to limitations in identifying a clear cause of symptoms in those with ME/CFS, medical practitioners have often attributed symptoms to psychology alone, adding to the rejection experienced by those with the condition [37]. Recognition of ME/CFS as a biological condition, as opposed to psychosomatic, has taken decades of advocacy, and is still yet to be universally accepted by the medical community. Despite evidence of proposed pathophysiological mechanisms with plausible scientific rationale [5], those interviewed, who were interested in managing patients with Long-COVID, reported colleagues making comments such as *“This is all fairy dust, it doesn’t actually exist. Why have we got it on our agenda.”* Drawing from the history and management of ME/CFS may provide clues as to how Long-COVID could be treated, given the similarities between the two.

Exercise therapy

A significant finding of this study was that clinician perceptions of what constitutes graded exercise therapy might be responsible for some of the opposing viewpoints surrounding its appropriateness for people with Long-COVID. Large health organisations such as the National Institute of Health and Care Excellence (NICE) [25] and the World Health Organisation (WHO) caution the use of graded exercise as a therapy for people with Long-COVID. The most widely accepted use of exercise as therapy is through an individualised, symptom-titrated approach to progressing physical activity or exercise within the constraints of an individual’s post-exertional malaise or post-exertional symptoms exacerbation [38]. In our interviews, both those in favour of graded exercise therapy and those opposed described a similar rehabilitation process of what they considered as optimal i.e., an approach of individualised symptoms-titrated physical activity. Those in favour thought this approach fell under the banner of graded exercise due to the view that anything that builds on a previous activity is graded, while those opposed thought “graded exercise” implied preordained incremental increases in intensity regardless of a patient’s presentation or response to exercise. This differing understanding of what constitutes a graded approach has previously been demonstrated in published literature surrounding post-exertional malaise [39].

Clinicians raised concerns about public opposition to any intervention that incorporated exercise or physical activity, often referring to social media as responsible for influencing the opinions of potential rehabilitation consumers. A recent study evaluated social media posts where influencers were discussing medical tests which had a potential for overdiagnosis [40]. The study demonstrated that messaging from influencers was overwhelmingly misleading and lacked evidence, demonstrating concerns over how social media could persuade viewers to hold an opinion not in line with best-quality research evidence. Whilst clinicians both for and against graded exercise therapy (based on their views about how it is defined) may agree that an individualised symptoms-based exercise or physical activity program can be appropriate, there is a strong potential that social media influencers in the Long-COVID space may advocate against all exercise-based interventions on face-value, potentially limiting treatment options for those who might benefit from exercise rehabilitation. However, social media can also be a supportive tool for those experiencing Long-COVID. As aforementioned, social media was a medium to which those with lived experience of post-COVID sequelae were able to unite to identify and name the condition [8].

Limitations

This study involves interviews with a multidisciplinary group of health professionals who provide rehabilitation services or who refer to rehabilitation services. We believe thematic saturation was reached for physical rehabilitation approaches, especially given thematic saturation in homogenous groups has been suggested when interviewing between 9 and 17 participants [41]. However, 21 interviews may not have been adequate to collect discipline-specific opinions surrounding Long-COVID rehabilitation due to the small number of participants in some categories like general medical practitioners. Additionally, we did not enable member checking due to logistical issues and participant time constraints.

Future research should consider exploring clinician views around diagnosis, considering the varied clinician perspectives on the relative value of diagnostic investigations. Additionally, future studies should further explore clinician differences in understandings of graded exercise therapy and in the messaging that surrounds exercise-based rehabilitation approaches.

Conclusion

This study provides new insights into how clinicians conceptualise and navigate the complexity of Long-COVID. The study highlights varied opinions on appropriate terminology and how this impacts care. Issues surrounding diagnosis were explored as well as the divergent approaches clinicians take to form diagnoses, which may lead to fragmented care. Clinicians expressed uncertainty with how Long-COVID is managed in healthcare, whether through lack of available evidence for interventions or through reflection on experiences where they felt other health professionals required upskilling in managing people with Long-COVID. Finally, the role of exercise therapy was explored with a focus on how semantics may play a role in disagreement about the role of graded exercise therapy in Long-COVID populations as well as how such disagreement may fuel public advocacy against the use of any exercise interventions, thus impacting the care of those who may benefit from physical rehabilitation.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Ethical statement

The study received ethical approval from the Sydney Local Health District (SLHD) Human Research and Ethics Committee (Protocol No X23-0215 & 2023/ETH01265). All participants provided informed consent.

Author contributions

CRedit: **Jack M. Reeves**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft; **Justin McNab**: Formal analysis, Investigation, Methodology, Project administration, Validation, Writing – review & editing; **Lissa M Spencer**: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – review & editing; **Ling-Ling Tsai**: Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – review & editing; **Andrew J. Baillie**: Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – review & editing; **Jennifer A. Alison**: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Supervision, Writing – review & editing.

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Data availability statement

Data may be made available following further ethical approval.

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