

Still Many Questions But a Few More Answers: Long COVID and Pulmonary Rehab

Transcript

Hello everyone and welcome back to the LungFIT Podcast! This episode I'm going to talk about Long COVID, the impact it has on patients and how pulmonary rehabilitation can help. We may be on the other side, or is it another side? of the COVID-19 pandemic, however, not everyone managed to overcome COVID-19 the same way. In 2020 we had a LungFIT episode called "Some Questions Related to COVID-19 and Pulmonary Rehabilitation" and, true to that title, it was really all questions. We didn't know much then. Now of course it's 2023, and we still have a lot of questions, but we have also learned a lot that is relevant to pulmonary rehab.

A significant percentage of people (15% according to Stats Canada) reported that they still experienced illness-like symptoms 3 months or more after a positive COVID-19 test or suspected COVID-19 infection. The percentage is much, much, higher in people who have been hospitalized with Long COVID. This amounts to approximately 1.4 million Canadians, at a minimum. Surprisingly, the data also reports that women are at a higher percentage than males (at 18%) of experiencing post-COVID-19 symptoms. Although there are now several diagnostic names, patients with these ongoing symptoms are using the term Long COVID and so that's what I'll use here.

So what is long COVID-19, how is it characterized and what are the symptoms?

First thing to say is – there is a lot we don't know when it comes to understanding Long COVID. STILL! The COVID-19 virus affects many body systems, including the pulmonary system of course, but there isn't a clear causal pathway between the initial COVID-19 infection and the subsequent development of Long COVID. Multiple hypotheses on the etiology of Long COVID have been proposed, including but not limited to: immune dysregulation, reservoirs of SARS-CoV-2 in the tissues; and endothelial dysfunction. There have been some indicators in terms of who is most susceptible to Long COVID, these risk factors include female sex as I mentioned; pre-existing Type 2 diabetes; Epstein-Barr reactivation; severe initial infection, and increasing age, but many people without these risk factors develop Long COVID.

The WHO characterizes Long-COVID as having symptoms such as fatigue, breathlessness, cough, cognitive dysfunction (including lack of mental focus, brain fog or forgetfulness). Other reported symptoms include joint pain, chest pain, headaches, and sleep disturbances, present at 3 months post-infection. New-onset conditions associated with Long COVID can be serious, including cardiovascular, thrombotic, and cerebrovascular disease, type 2 diabetes, myalgic encephalomyelitis (or ME), and dysautonomia, especially postural orthostatic tachycardia syndrome (or POTS). While these are some of the most commonly reported symptoms and conditions, this is not an exhaustive list. Over 200 signs and symptoms have been reported. Long-COVID can severely interrupt a person's activities of daily living, their mobility, and their health-related quality of life which can have a long-lasting impact and potentially long term disability. People with Long COVID-19 who already have a chronic disease may experience an even greater decrease in their quality of life. Their symptoms can also be more severe and longer lasting as well.

On top of the physical aspects of living with Long-COVID, it is important to acknowledge the productivity and economic aspects. If you've been working in pulmonary rehab for awhile your patients may be older, and likely already retired. Although increased age is a risk factor for Long COVID, the highest percentage of people diagnosed are between 36 and 50 years old, which are prime earning years for most people. And the economic impact of this serious disability on people under the age of retirement is enormous. A recent 2023 study by Perumal et al. reported that in the USA alone, up to 4 million people have been

unable to work due to Long COVID with the total burden estimated at between 2.6 and 3.7 trillion dollars. In 2022, David Cutler of Harvard University estimated this economic impact falls into three components:

1. The cost associated with worse Quality of life (QALY), which is commonly included in economic impact analysis. This comprised 59% of the overall cost, or **\$2.195 trillion**.
2. Lost earnings of **\$997 billion**
3. Medical care spending: **\$528 billion**

So Long COVID can cause severe enough disability that a person is unable to work, which impacts that person and their family. It has an economic impact on society as detailed above. And it has an impact on the workforce – many people who got COVID and subsequently Long COVID were front-line workers, including health care professionals. You may have colleagues who have this. And losing multiple people in many industries has a downstream effect on us all.

How is Long-COVID19 diagnosed? Well, currently there are no single diagnostic test available to test for Long-COVID. There are diagnostic tools available to identify some potential aspects of Long COVID, for example, tilt tables for POTS, or pulmonary function tests for airflow limitation. And for those of you who dream of having dogs more involved in health care, there is one study that found that sniffer dogs could detect individuals with Long COVID based on their sweat samples! But we still don't have a specific biomarker test for Long COVID. And combined with the fact that many people now have to self-test, and so there is no objective, recorded result which confirms they even had the COVID19 infection to begin with, this makes it difficult for patients who are seeking care for their symptoms or disability support.

But if Long COVID is suspected, the healthcare provider will review the medical history of the patient which will include information about the COVID19-19 infection, previous chronic illnesses, and any subsequent symptoms post-infection. A physical examination may be done to assess the patient's overall health. The patient may be referred to a specialist such as a respirologist, cardiologist or neurologist in complex cases or where the burden of severity is heavy. Because of the inconsistent and varying nature of Long-COVID, it can be difficult to get a diagnosis of Long-COVID. We are still in a period of limited understanding about the disease and research is still ongoing.

So what about treatment? I hear there are potential pharmacological advances in treating and/or preventing Long COVID, but that's not my area of expertise and I won't attempt to describe them here. I'll focus in on rehab, because whether the period of Long-COVID is long or short, there is a role for rehab to support people in their recovery, or mitigate the impact of the symptoms. For those that are hospitalized, early mobilization is recommended to reduce the risk of ICU- or hospital-acquired weakness. Early mobilization exercises have to be very gradual and focus on mobility – aerobic exercise may exacerbate symptoms.

Once over the acute, infectious phase, patients may be eligible for rehab. Physical deconditioning and respiratory impairments are typical indicators for pulmonary rehab -- which may play a big part in helping those with Long COVID in their symptom management and recovery. Because pulmonary rehab is multidisciplinary, it has the capacity to address multiple issues the patient might be facing. And to reinforce, I'm speaking from my experience of pulmonary rehab and my understanding of the literature here. And you're likely to have expertise in pulmonary rehab too, that is probably how you found your way to this podcast! Of course, pulmonary rehab isn't the only type of rehab that would be beneficial, and where someone with Long COVID goes for rehab may depend on what their predominant symptom is. I think that Long COVID has also reminded us how silo-ed our rehab delivery models are – we have rehab for all these individual body systems but Long COVID can affect so many body symptoms, and be different from one patient to the next. Perhaps we'll need stand-alone Long COVID rehab, but

until then people are likely referred to whatever is available and where people have some experience in treating Long COVID. But I think all rehab programs will need to likely quickly be a lot more comfortable with other treatments found in other rehab programs, in order to best care for patients' symptoms.

Pulmonary rehab uses exercise as one of its main foundational components. As we know, committing to a regular, progressive exercise plan can help build tolerance, increase endurance, improve mobility and improves quality of life. However, we need to take a different approach with patients with Long COVID. We need to screen for conditions which may worsen if the patient undergoes an exercise program. The Canadian Physiotherapy Association has a nice overview of conditions to screen for, specifically POST-EXERTIONAL SYMPTOM EXACERBATION, CARDIAC IMPAIRMENT, OXYGEN DESATURATION, DYSAUTONOMIA, FUNCTIONAL COGNITION AND COGNITIVE COMMUNICATION IMPAIRMENTS, VOICE AND SWALLOWING IMPAIRMENTS, HEARING IMPAIRMENTS, AND PSYCHOLOGICAL IMPAIRMENTS. I'll put the link in the show notes. They actually suggest that all patients be screened, since many people got COVID and don't know it, and so might not know that they have Long COVID either, especially if they have pre-existing conditions or other possible explanations for symptoms.

The presence of debilitating fatigue, ME, or post-exertional symptom exacerbation in patients with Long COVID likely means no **aerobic** exercise altogether. The World Health Organization has created Long COVID Rehabilitation Guidelines, and have a strong recommendation which I will quote: *"In adults with post COVID19 condition (which is their term for Long COVID), exertional desaturation and cardiac impairment following COVID19 should be ruled out and managed before consideration of physical exercise training. While orthostatic intolerance (POTS) and post-exertional symptom exacerbation are amenable to rehabilitation, their presence will require interventions to be modified in view of these diagnoses for rehabilitation to be safe"*. So if you don't have experience with POTS and post-exertional fatigue, or excellent guidance and support from those who do, then you may consider not accepting people with these symptoms in your program. You may do more harm than good. If patients have cardiac impairment, you may need to consider having them go to cardiac rehab where they can be more closely monitored. If they have exertional desaturation, they may need to be evaluated for underlying reasons, and be stabilized on supplemental oxygen, before starting rehab.

If they are cleared for rehab, when considering their exercise program, you will likely need a different approach than your patients with COPD or ILD. Pacing is a key feature of caring for people with Long COVID, and we need to start SLOW, with simple functional exercises such as range of motion, resistance exercise, and low-intensity activity with close monitoring of any increase in symptoms. This monitoring includes teaching your patients to be aware of any increase in symptoms 24-72 hours post-exertion. There are questionnaires available for this – the CPA guidance document provides an example. Most papers don't have specific exercise programs for patients with Long COVID – the mantra seems to be: be conservative, start slow with a focus on function and what is needed for activities of daily living (think: sit-to-stand, mobility, light resistance, light physical activity, lots of monitoring). Your patient is your evidence! And remember that an increase in symptoms post-exercise might not be an increase in physical symptoms – patients might report changes in cognitive, communication, or emotional function that may be an indication to reduce the intensity of exercise.

Providing education through classes covering different topics around lung health, physical activity and management techniques may be helpful. Again, some adaptation to our typical chronic lung disease education curriculum is warranted. We *don't* know the progression or potential of recovery for people with Long COVID, and so education on prognosis will look quite different than for our patients with COPD or ILD. Focusing on immediate needs might help – such as energy conservation, strategies for managing ADLs, and pacing activity if fatigue and myalgia is present. Another important topic is control of breathing – teaching patients the positions and breathing techniques that we use in rehab will be

important to help reduce breathlessness. There are some very nice patient education tools out there – the National Health Service in the United Kingdom has a dedicated website called “Your COVID Recovery” which provides information about COVID19 and Long COVID. It doesn’t get much into specifics about post exertional malaise, it is more of a general education guide. If you have patient education resources that you’re happy with, please let me know.

We may also need to provide a lot of support regarding adaptive aids. Again, a reminder that you might have a Long COVID patient population that is much younger than your usual patients, and they might not have heard of aids like bath boards to reduce fatigue while bathing.

Many pulmonary rehab programs use a lecture and discussion style of patient education, but people with ‘brain fog’, or cognitive dysfunction, may find that style of patient education difficult. Shorter sessions, inviting family to attend, having all information in written formats, and repetition may help your patient’s take in the important material. For many people, they may have been very healthy prior to their COVID19 infection, and the transition to disability may have been very abrupt and distressing. They have had a different course of illness than those with COPD or ILD, whose disease may have been characterized by several weeks, months or years prior to diagnosis and/or coming to your rehab program. So the whole rehab process, and the education curriculum, may be very overwhelming. Go slow, and provide the information in written format so they can review it when they are ready.

But, on the flip side, we have the social support that occurs within the program. We know this to be such an important part of rehab -- life with a chronic disability can be tough and isolating and when you meet other individuals who are in a similar situation as you it can be helpful. This psychosocial support is as important as the physical benefits. Attending a regular program also puts the patients directly in touch with supportive healthcare providers. This has the added benefit of helping the patient get rapid care in case something new or worrying occurs.

Again, early days yet, but what are the reported benefits of rehab for those with Long COVID? I’ll focus on the pulmonary rehab literature, but again will reinforce that other types of rehab are also conducting research with results to report. But from the pulmonary rehab world, these are some of the benefits reported. Most studies have small sample sizes, or not the most rigorous of research designs.

But to summarize the potential benefits of pulmonary rehab for those with Long COVID.

- improved exercise tolerance
- increased endurance and improve mobility
- improved quality of life
- symptom relief
- reduced stress
- mitigated loss of physical function
- provided education & knowledge
- gained new skills & tactics
- encourage better medication use
- psychosocial support
- increased social interactions
- ability to talk to someone about symptoms, and other experiences.

BUT I want to reinforce that these effects are mostly published in small clinical trials, case studies, or observational studies. Funding for rehab studies is happening so it will be awhile before we see large, multi-centre trials with multiple exercise arms reported. So we have to continue to proceed cautiously.

Some closing points to consider: Capacity in rehab programs is already quite stretched and so adding this new cohort of patients (especially in the volume we are seeing) may be difficult. I mentioned this in 2020 and its still the same now. Should we be adding Long COVID patients to existing pulmonary rehab programs, when there isn't enough capacity for those who are our typical patients, those with COPD or ILD? Because of the complexity of these patients, should governments create Long COVID-specific programs? Do we have the health human resources for a whole other branch of rehab? These are all important points to acknowledge.

While I might be preaching to the choir about pulmonary rehab in long-COVID, I do think it is an important topic to discuss. There are still so many unknowns with this virus, and finding ways to help support the people who are living with this condition is very important. But it isn't a cut-and-paste with our typical pulmonary rehab, we will need to enhance our skills to address some of the signs and symptoms that we might not be as familiar with. More attention to screening and monitoring is key here.

Feel free to message me and tell me about what is happening in your program – are you seeing people with Long COVID? Does your program have the capacity to include these patients? I would love to hear from you about this.

Anyway that is all for now – if you enjoy our content please take a minute to rate & review our show! Thanks for listening & bye for now.