

Long COVID, Episodic Disability and Rehabilitation

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SUMMARY POINTS & RECOMMENDATIONS

- Long COVID presents with multi-dimensional clusters of symptoms that can fluctuate, sometimes unpredictably, whereby symptoms adversely affect general well-being and ability to perform day-to-day activities, exercise, or work.
- We propose that Long COVID should be conceptualised as an episodic health condition, characterised by health-related challenges (or disability) that may be multi-dimensional, episodic, and unpredictable in nature.
- Dimensions of disability experienced by people living with Long COVID may include physical, cognitive, mental and emotional health challenges, difficulties with daily activities, challenges to social inclusion, and uncertainty, with uncertainty and worrying about the future a key dimension of disability.
- The role for rehabilitation is critical for people living with Long COVID, offering a goal-oriented, person-centred approach to prevent, mitigate, and address episodic disability.
- There is a need to establish valid and reliable measures of episodic disability, assessing effectiveness of rehabilitation approaches and interventions, and building on existing international collaborations and community-engaged partnerships to advance practice, research, and policy.

Introduction

A growing number of individuals are living with persistent and prolonged signs and symptoms following infection consistent with COVID-19, referred to as Long COVID or Post-COVID Condition. Defined by the [World Health Organization](#), “Post COVID-19 condition or Long COVID occurs in individuals with a history of probable or confirmed SARSCoV-2 infection, usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis. Common symptoms include fatigue, shortness of breath, cognitive dysfunction but also others and generally have an impact on everyday functioning. Symptoms may be new onset following initial recovery from an acute COVID-19 episode or persist from the initial illness. Symptoms may also fluctuate or relapse over time.”

An estimated 144 million individuals are living with Long COVID globally. A systematic review involving 50 studies, concluded the pooled global prevalence of Long COVID globally was 43% among hospitalized (53%) and non-hospitalized patients (34%) ([Chen et al, 2022](#)). Systematic review evidence examining symptoms among individuals after COVID-19 reported that 38-72% were living with ≥ 1 symptom for at least 2 months, from COVID-19 onset and up to 54% were living with persistent symptoms for 6 or more months ([Nasserie, 2021](#); [Domingo, 2021](#); [Michelen, 2021](#); [Whitaker 2021](#); [Groff, 2021](#)).

As of June 2022, an estimated 2 million people in the United Kingdom (3.1% of the population) self-identified experiencing symptoms continuing greater than 4 weeks after COVID-19, and among those with Long COVID, 30% had COVID prior to when alpha became the main variant, 12% in the alpha variant period, 21% in Delta period, and 31% in the Omicron period, suggesting Long COVID can develop regardless of variant ([Office of National Statistics in the UK, June 2022](#)).

The long-term trajectory of Long COVID remains unknown. Therefore conceptualising disability in Long COVID is essential for better understanding the lived experiences and health-related challenges of people living with and affected by Long COVID, to inform effective rehabilitation approaches and interventions to enhance clinical practice, policy, and research.

Long COVID and Episodic Disability

Long COVID is characterized by ‘clusters of symptoms’ that can overlap and ‘fluctuate and change over time’, described as ‘prolonged’, ‘relapsing and remitting’, which may be termed episodic ([Brown & O’Brien, 2020](#)). Episodes may fluctuate with Long COVID within the day, between weeks, or over a longer continuum. The multi-dimensional, episodic and sometimes unpredictable health consequences of Long COVID resembles **episodic disability**, a concept derived from the context of HIV, where health challenges can fluctuate daily or over longer periods of time ([O’Brien et al, 2008, 2009](#)).

Fatigue continues to be the most common reported symptom with Long COVID, among 55% of those self-reported living with Long COVID in the UK followed by shortness of breath (32%), cough (23%) and muscle aches (23%). ([Office of National Statistics in the UK, June 2022](#)). A community-led online survey across 56 countries highlighted an average of 56 symptoms spanning nine organ systems including fatigue, post exertional malaise (PEM), and cognitive dysfunction, with 86% of respondents experiencing relapses in symptoms triggered by exercise, physical or mental activity, or stress ([Davis et al, 2021](#)).

The multi-dimensional nature of disability experienced by people living with Long COVID, can adversely impact daily function, return to employment, family life, relationships, and ability to care for others. For instance, among those living with Long COVID, 71% reported adverse affects to day-to-day activities, with 20% reporting significant limitations to daily activities ([Davis et al, 2021](#)). Long COVID further disproportionately affects people aged 35-59 years (prime career building years), females, people living in deprived areas, those working with social care, teaching, education or health care, and those with other activity limiting conditions or disability ([Office of National Statistics in the UK, June 2022](#)).

These health challenges can affect return to employment, relationships, access to services, stigma, and mental health, further contributing to disability after acute COVID-19. Among respondents in a community-led survey led by the [Patient-Led Research Collaborative](#), 45% were working reduced hours, and 22% were not working at all due to their illness. ([Davis et al, 2021](#)).

Episodic Disability Framework in Long COVID

Utilising an existing framework of disability developed from others living with episodic illness can provide a foundation for understanding disability experienced among people living with Long COVID.

The **Episodic Disability Framework** was derived from the perspectives of people living with HIV in Canada to characterise the multi-dimensional and sometimes fluctuating nature of health-challenges ([O’Brien et al, 2008, 2009](#)). The Episodic Disability Framework provides a novel way to conceptualise disability experienced by people living with Long COVID. For instance, someone living with Long COVID may experience **dimensions of disability** spanning physical health challenges (fatigue, post-exertional symptom exacerbation, or shortness of breath), cognitive health challenges (difficulty thinking or concentrating; “brain fog”), resulting in mental-emotional health challenges (anxiety, or depression), difficulties carrying out day-to-day activities (showering, meal preparation, or walking), and impacting challenges to social inclusion (meaningful life roles or employment). These disability dimensions may be influenced by **contextual factors**, exacerbated by stigma including a lack of belief of health challenges, or alleviated by practical and emotional support (eg: peer support) and rehabilitation services. Furthermore, disability dimensions can be **triggered** by factors such as physical activity or exercise, prolonged cognitive activities, or other health conditions.

A team of researchers, clinicians, and community members are collaborating on a [CIHR-funded Long COVID and Episodic Disability Study](#), to characterize the multi-dimensional and episodic nature of disability experienced by adults living with Long COVID. Given the importance of terminology to provide clarity of understanding and communication among community and health providers, we recommend the use of the term ‘episodic disability’ to characterise the multidimensional, episodic and unpredictable health-related challenges associated with Long COVID.

Uncertainty and Long COVID

Uncertainty and worry about the future is a key feature of disability experienced among people living with long COVID. Uncertainty was found to be a key dimension of disability and predictor of mental-emotional health and social inclusion for adults living with HIV ([O’Brien 2019](#)). In Long COVID, the impact of living with the uncertainty of when an episode of disability might arise, the severity and duration of that episode, and the long-term implications on health, including the financial, practical, and emotional consequences are unknown.

Uncertainty experienced among people living with long COVID includes not knowing when an episode of disability might arise, the severity and duration of that episode and the long-term implications on health and life decisions. The long term outcomes and trajectory of Long COVID recovery remain unknown, and new uncertainty exists about what might occur in the event of a re-infection of COVID-19 among people living with Long COVID. Diagnostic uncertainty exists whereby Long COVID can be difficult to ascertain, particularly for those without a COVID-19 PCR, antigen or antibody test, and can add complexity to those faced with challenges accessing employment or income benefits after leaving the workforce during illness, further contributing to disability and reduced quality of life after acute COVID-19. Financial uncertainty may exist for those unsure if, when, or how to return to workforce, as well as uncertainty among employers and human resource professionals as to how to accommodate and facilitate return to work. Finally, uncertainty also exists among health and rehabilitation professionals as to how to safely and effectively treat people living with Long COVID.

Role of Rehabilitation in Long COVID

With the ‘severely disabling’ potential of Long COVID, the role for rehabilitation is critical to help prevent, address, mitigate disability and enhance health outcomes. [Rehabilitation](#) (including physiotherapy and occupational therapy) involves any services or providers who address or prevent disability focused on the physical, mental-emotional, cognitive and social domains of health and disability, and hence is well-positioned to address episodic and multidimensional disability among people living with Long COVID. Rehabilitation should be disability focused, goal-oriented, person-centred, focused on function, tailored to an individual’s goals, abilities, and interests.

Rehabilitation is not limited to exercise and physical activity. World Physiotherapy has been instrumental in developing safe and effective rehabilitation approaches in Long COVID. Caution with exercise has been recommended in physiotherapy guidelines as exercise is [not a safe rehabilitation intervention](#) to treat fatigue among people experiencing [post-exertional symptom exacerbation](#). It is important to consider the length and burden of assessments and whether they have the potential to trigger an episode of post exertional malaise. This is because physical exertion is a common trigger for symptom exacerbation among people with Long COVID. See the [World Physiotherapy Briefing Paper](#) on safe rehabilitation approaches for people living with Long COVID.

There is a critical need to assess the impact of rehabilitation interventions to reduce episodic disability and enhance health outcomes for people living with Long COVID. Development of a robust research agenda involving disability and rehabilitation will be important for moving forward including a coordinated response, evidence to support; appropriate safe and timely and effective rehabilitation strategies, interventions and models of care are needed.

Measurement of Episodic Disability in Long COVID

To provide optimal care in the context of Long COVID, we need comprehensive, feasible tools to understand the profile and episodic nature of disability over time. Standardized patient reported outcome measures designed to capture the nature and extent of disability and its fluctuation over time are critical to guide the provision of care, determine the effectiveness of interventions, and inform workplace policies (such as phased return to work) and access to services (such as rehabilitation) for people living with Long COVID.

The [HIV Disability Questionnaire \(HDQ\)](#) is a patient-reported outcome measure which describes a range of health challenges a person might experience and the extent of fluctuation to better address the disability needs of people with chronic illness. Based on the Episodic Disability Framework, this tool is the first known measure of episodic disability, addressing gaps in previously existing health status measures to capture uncertainty and elements of social inclusion (relationships, employment). The HDQ possesses reliability and validity for use with people living with HIV in Canada, Ireland, United Kingdom, and United States ([O'Brien 2015](#), [O'Brien 2019](#), [Brown, 2019](#)).

The newly formed **Episodic Disability Questionnaire (EDQ)** is the first known measure of episodic disability, addressing gaps in previously existing health status measures to capture uncertainty and elements of social inclusion (relationships, employment). There is an opportunity to build from existing validated instruments in episodic disability with other chronic episodic conditions, to identify key features of disability specific to persons living with Long COVID, to help indicate areas in which to direct supports, interventions, and resources. Members of the international Long COVID community ([COVID Long Haulers Support Group Canada](#), [Long COVID Support UK](#), [Patient-Led Research Collaborative](#), [Long COVID Ireland](#), and [Long COVID Physio](#)) who are knowledge users and collaborators on the [CIHR-funded Long COVID and Episodic Disability study](#) are working to establish the Episodic Disability Questionnaire.

Foundational data on the presence, severity and episodic nature of disability and contextual factors that may influence disability are critical for guiding treatment approaches. Universal measurement of disability over time may facilitate clinical management, specifically tracking episodic disability trends to better tailor rehabilitation resources and approaches among people living with chronic episodic conditions. Long-term measurement of disability will contribute to existing databases to document longitudinal profiles of disability and situate disability as a key construct in health services research. This will allow tracking of disability trends to evaluate implementation of interventions and policies for enhancing labour force participation and income support that acknowledge the fluctuating and unpredictable nature of chronic illness.

Community engaged rehabilitation response to Long COVID rehabilitation.

Finally, taking a community-engaged response to Long COVID rehabilitation will help to foster timely, relevant and meaningful interventions and approaches to rehabilitation, and the application of research

evidence about appropriate service planning and delivery. Disability and rehabilitation-focused responses should include people living with and affected by the pandemic.

International partnerships and collaborations fostered in other health conditions provide a strong foundation from which to establish a coordinated, relevant and meaningful approach for advancing rehabilitation for people living with Long COVID. Access to timely, safe, effective, and accessible rehabilitation is a critical area in need of development and highlights the opportunities and importance of partnering with other chronic conditions to foster a ‘strength in numbers approach’ with other chronic and episodic illnesses to advance policy and programming related to Long COVID rehabilitation such as Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS).

In Summary

The role for safe and effective rehabilitation is critical in the context of Long COVID. It is essential to better understand episodic disability experienced by people living with Long COVID, establish tools to measure the presence, severity, and episodic nature of disability, in order to target timely and appropriate rehabilitation interventions and mitigate disability to enhance health outcomes for people living with Long COVID. While evidence continues to emerge, rehabilitation professionals are well positioned to address episodic disability in Long COVID. Opportunities exist to build on successful disability and rehabilitation models from other chronic and episodic illnesses, in the context of Long COVID.

For more information: [Long COVID Physio](#) is an international patient-led association of physiotherapists living with Long-COVID and allies which provides a wealth of resources and videos on Long COVID, research evidence, and safe approaches to rehabilitation.