

Kelly K. O’Brien^{1,2}, Darren A. Brown, OBE^{2,3}, Kiera McDuff¹, Natalie St. Clair-Sullivan^{4,5}, Soo Chan Carusone⁶, Catherine Thomson², Lisa McCorkell⁷, Hannah Wei⁷, Susie Goulding⁸, Margaret O’Hara⁹, Niamh Roche¹⁰, Ruth Stokes¹⁰, Mary Kelly², Angela M. Cheung^{1,11}, Kristine M. Erlandson¹², Richard Harding¹³, Jaime H. Vera^{4,5}, Colm Bergin^{14,15}, Ciaran Bannan^{14,15}, Brittany Torres¹, Nisa Malli⁷, Lisa Avery^{1,11}, Patricia Solomon⁶

¹ University of Toronto; ² Long COVID Physio; ³ Chelsea and Westminster Hospital NHS Foundation Trust, London, United Kingdom; ⁴ Brighton and Sussex Medical School, University of Sussex, Brighton, UK; ⁵ Royal Sussex Hospital, Brighton and Sussex University Hospitals NHS Trust, Brighton, UK; ⁶ McMaster University, Hamilton, Ontario; ⁷ Patient-Led Research Collaborative; ⁸ COVID Long-Haulers Support Group Canada; ⁹ Long Covid Support, UK; ¹⁰ Long COVID Advocacy Ireland; ¹¹ University Health Network, Toronto, Ontario; ¹² University of Colorado, United States; ¹³ King’s College London, London, UK; ¹⁴ St. James’s Hospital, Dublin, Ireland; ¹⁵ Trinity College Dublin, Ireland;

Background

- Long COVID is characterized by a multitude of health symptoms that affect daily functioning and social participation.
- The **Episodic Disability Framework (EDF)** originally derived from the perspectives of adults living with HIV, characterizes the multidimensional and episodic nature of health-related challenges experienced by an individual.
- Episodic disability** is a term used by adults living with Long COVID to describe the trajectories of their health-related challenges, referencing relapsing or remitting fluctuations in symptoms and severity over time.
- A conceptual foundation of disability in Long COVID is essential for better understanding health-related challenges of people living with Long COVID and is critical for guiding measurement of the construct, informing health and rehabilitation approaches to enhance clinical practice, policy, and research.

Aim

To determine the applicability of the Episodic Disability Framework to conceptualize the health-related challenges experienced among adults living with Long COVID.

Methods

Study Design: Community-engaged qualitative study involving online semi-structured interviews with adults living with Long COVID (Dec 2021-May 2022).

Community Partner Networks and Organizations: This study involved a community-clinical-academic collaboration involving:

- Patient-Led Research Collaborative (PLRC)
- Long COVID Physio,
- Long COVID Support UK,
- COVID Long Haulers Support Group Canada,
- Long COVID Advocacy Ireland, and Long COVID Ireland.

Participants: Adults who self-identified as living with Long COVID via community organizations in Canada, Ireland, United Kingdom, and United States.

Recruitment & Sampling: Targeted recruitment via community organizations. We purposively recruited for diversity in age, gender identity, ethnicity, sexual orientation, and time since initial COVID-19 infection.

- Data Collection:**
- Semi-structured online interviews informed by the EDF to explore experiences of health-related challenges and how they were experienced over time.
 - Demographic questionnaire: personal, health and COVID characteristics.
 - All interviews were audio recorded and transcribed verbatim.

Analysis: Group-based qualitative analysis involving content analytical techniques.

Characteristics of Participants (n=40 participants; 10 per country)

Characteristic	n (%)	Characteristic	n (%)
Median age (Q1, Q3)	39 years (32, 49)	Living with Long COVID >1 year	33 (83%)
Gender		Employment Status Since Living with Long COVID	
Man	11 (28%)	Unable to work / on leave of absence	4 (10%)
Woman	25 (63%)	Changed employment role or job	6 (15%)
Non-binary	2 (5%)	Lost job or now unemployed	5 (13%)
Other (gender non-conforming)	2 (5%)	Reduced work hours	5 (13%)
		Unchanged employment status	
Experienced Relapse in Long COVID Symptoms	34 (85%)	Have Children	18 (45%)

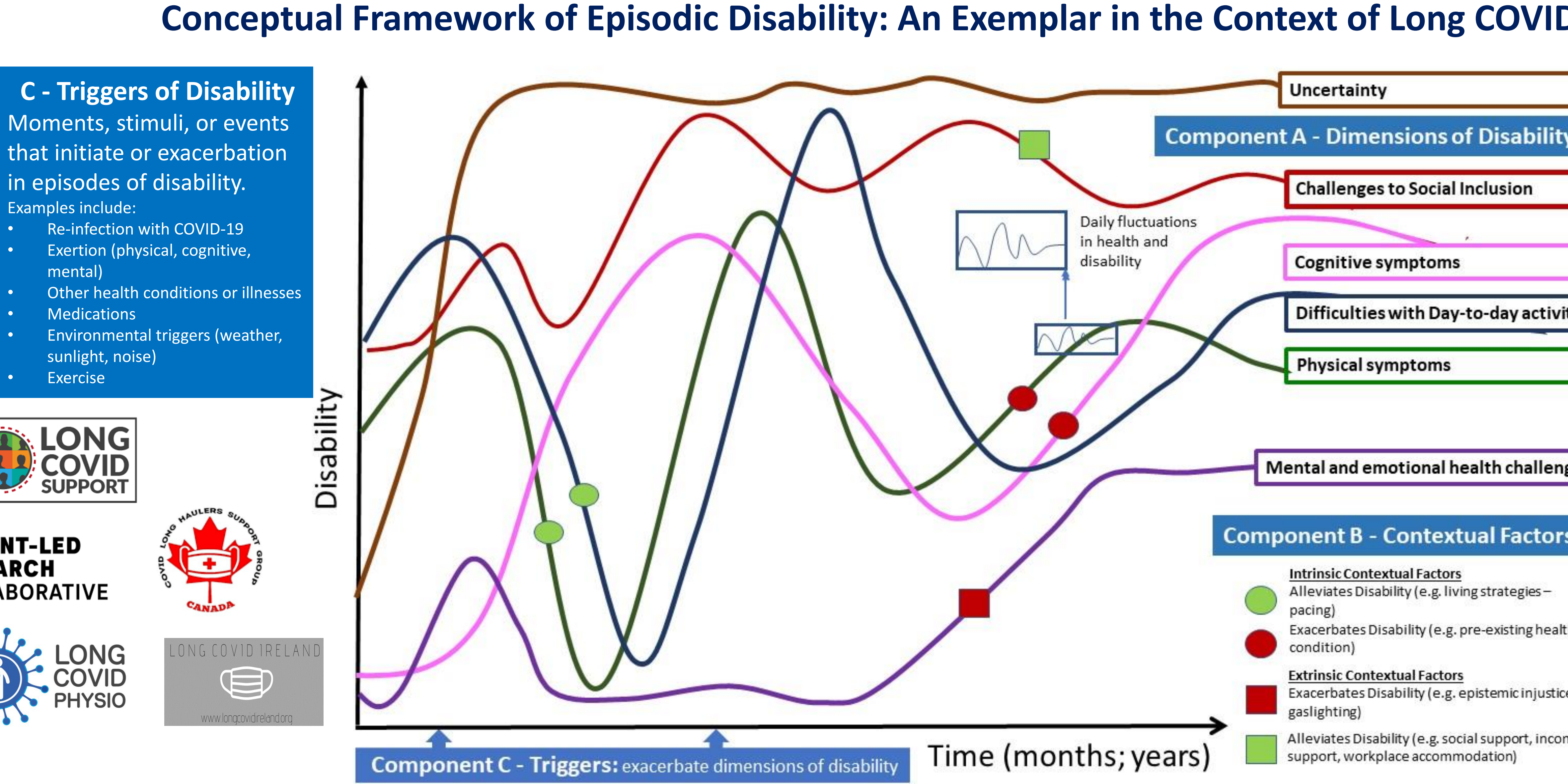
Experiences of Disability Living with Long COVID

Episodic disability as a continuum of health challenges with variable presence, severity and duration of health challenges over time; Disability included day-to-day health fluctuations (or fluctuations within a day), that may be super-imposed over the broader spectrum of disability experienced over months or years living with Long COVID.

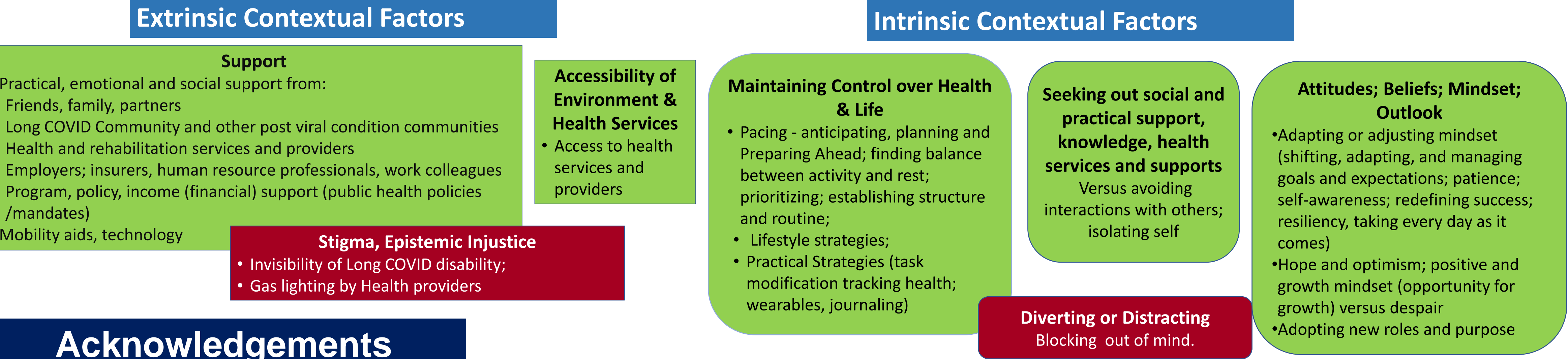
Not an all or nothing concept - a continual state of health challenges with changing presence, severity and duration of episodes over time.

Visibility and Invisibility of Disability: Some of which may be episodic while co-existing with permanent or constant aspects of disability.

Multidimensional Nature of Disability: Superimposed along the six dimensions of disability trajectories are the daily fluctuations in health.



B - Contextual Factors - Interact with an influence on dimensions of disability (exacerbate or alleviate)



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Results

A - Dimensions of Disability

Physical Symptoms

- Post-exertional symptom exacerbation
- Fatigue
- Weakness
- Dizziness
- Nausea
- Pain
- Skin sensitivity
- Hearing; vision; voice
- Sensory impairment
- Shortness of breath
- Swallowing; altered taste and smell
- Weight loss or gain
- Hair loss
- Persistent cough, sore throat; fevers
- GI issues
- Cardiac issues
- Menstruation changes
- Etc...

Difficulties with Day-to-Day Activities

- Mobility (ambulation; stairs; driving)
- Sitting upright
- Reading
- Bathing; showering
- Dressing
- Brushing teeth
- Meal preparation
- Cleaning
- Shopping (e.g. groceries)
- Going to appointments

Cognitive Symptoms

- Post-exertional symptom exacerbation
- Cognitive endurance
- Executive function, word finding, and communication (written and oral)
- Concentration
- Memory (short-term; long-term; working)
- Information processing (reading)
- Multi-tasking

Social Inclusion

- Recreation; leisure and other social activities
- Personal relationships
- Social isolation (loss of friendships, relationships, social networks)
- Caregiving and social roles
- Work, employment, school
- Financial challenges, (financial and housing insecurity, instability, student loans)
- Disruption to, and loss of retirement plans and goals

Mental-Emotional Health Challenges

- Post-exertional symptom exacerbation
- Grief, devastation, loss (function, health, relationships, employment, career, finances)
- Anxiety or depression
- Stress
- Fear (relapse, crowds, re-infection)
- Anger, mood swings, irritability
- Hopelessness; suicide ideation
- Loneliness

Uncertainty about the Future

- Uncertainty and worry about the future; unpredictability of episodes, uncertainty about triggers of episodes, their sources, and treatments for Long COVID
- Worry about future health, ability to work, have a family, fulfill family and social roles; financial and housing security
- Implications on health and future life decisions (e.g. family, return to work); consequences of uncertainty on daily function and social inclusion.

Conclusions

- The Episodic Disability Framework conceptualizes experiences of disability among adults living with Long COVID including dimensions, contextual factors and triggers of disability.
- Provides a conceptual foundation to advance future measurement of disability and target approaches for health and rehabilitation services and interventions.
- Strengths:** International and community-engaged approach, involving persons with lived experiences of Long COVID across five community networks in four countries.
- Limitations:** Sample includes English-speaking persons from high income countries; majority were women, white, and living with Long COVID for more than a year, and able to participate in an online interview.
- Current work is underway to measure episodic disability and assess the measurement properties of an Episodic Disability Questionnaire with adults living with Long COVID.

