

PRESENTED AT MAPS WEBINAR
MARCH 2023

OVERCOMING BARRIERS TO PATIENT-CAREGIVER ENGAGED RESEARCH

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Introduction

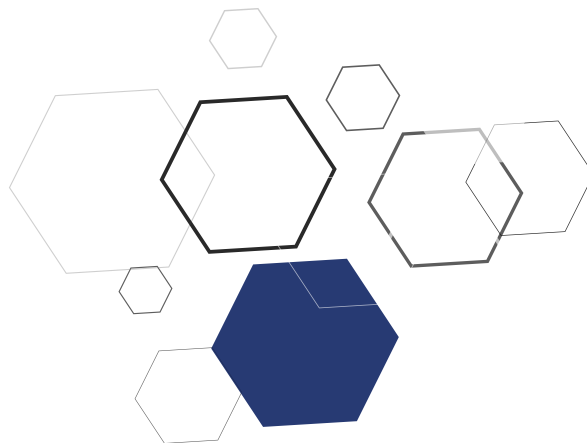
Patient-caregiver (PC) engaged research is medical research that is conducted with or by PCs rather than to or for them. PCs serve not only as study participants but assist with tasks traditionally carried out by researchers such as identifying research priorities or selecting outcomes measures. PC-engaged research can result in effective, practical, acceptable treatments; generate new ideas; improve participant enrollment and retention; and save money and time. However, publications regarding this type of research has mostly focused on the perspectives of research organizers and scientists rather than PCs themselves.

This presentation will focus on PC-engaged research from the viewpoint of PCs. I will share survey findings from PCs affected by myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS) and long COVID (LC). Both are complex, chronic medical conditions that share similar symptoms, often begin following an infection, and currently do not have disease-modifying treatments. Patients often encounter medical and scientific professionals who doubt their lived experiences and recommend harmful treatments. Thus, patient-engaged research is especially relevant for these fields.

The barriers and solutions to PC-engaged research discussed in this talk may be relevant and applicable to other chronic medical conditions.

What is myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)?

- A chronic, disabling medical condition which affects millions of men, women, and children globally.
- After a seemingly mild infection, patients fail to recover and remain sick for years and decades.
- Common symptoms: severe fatigue, unrefreshing sleep, problems thinking, and dizziness/palpitations upon sitting or standing up.
- Key symptom: post-exertional malaise. Symptoms are exacerbated for a prolonged period after mild physical or cognitive activity. For example, someone walking a block may need to rest in bed for a day.
- Decreases function significantly: 50% unemployed and 25% bed/ homebound.
- UNKNOWN cause, mechanism; NO gold standard diagnostic test; NO disease-modifying treatments
- Despite demonstrated biological abnormalities, ME/CFS is often wrongly attributed to deconditioning, exercise phobia, hypochondriasis, depression, anxiety, and laziness.



How are long COVID and ME/CFS related?

Up to 50% of long COVID patients also fit ME/CFS diagnostic criteria. Long COVID patients often experience severe fatigue, problems with thinking, sleep disturbances, dizziness, and exacerbation of these symptoms after exertion. The mechanisms that have been proposed for ME/CFS, such as viral reactivation, microbiome changes, and autoimmunity, are also being explored for long COVID. Finally, management techniques such as balancing activity with rest used in ME/CFS are also being used successfully in long COVID.



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Meet
Lily Chu, MD, MSHS

Lily Chu, MD, MSHS, has a background in internal medicine, geriatric medicine and health services research. Her career took a detour in 2006 when she came down with myalgic encephalomyelitis/ chronic fatigue syndrome (ME/CFS). Since then, she has worked to build bridges among healthcare professionals, scientists, and patient/ caregiver groups. Currently, she is the Vice President for the International Association for Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis. From 2012-2021, she was a member of the Community Advisory Board for the Stanford University ME/CFS Initiative. She has also collaborated with the CDC, FDA, NIH, Cochrane, and the US National Academy of Medicine. Dr. Chu hopes to bring all three of her perspectives (patient, physician, researcher) to this webinar.



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