Long COVID: Examining the Working Definition Clinical Education Perspective

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Long COVID & Fatiguing Illness Recovery Program ('LC&FIRP')

- CDC-supported collaboration between Family Health Centers of San Diego, Project ECHO/University of New Mexico, University of Washington, University of Colorado
- Specific Aims:
 - Improve care for patients with PASC/Long-COVID, ME/CFS and other post-infectious fatiguing illness (OPIFI)
 - Develop confidence of primary care providers in an urban FQHC safety-net clinic in managing these conditions
 - Test effectiveness of ECHO model vs. traditional CME
 - Establish national platform for dissemination of advances in understanding and best practices in management of PASC/Long-COVID, ME/CFS, OPIFI

The ECHO Model: Principles & Practices

- Leverage Technology
- Case-based Learning
- Sharing Best Practices
- Monitor and Evaluate Outcomes
- Interactive Learning Environment
- Collaborative Problem Solving
- Learning through didactics, by doing, from each other
- Honoring the Patient Perspective



- After an evidence-based review the Institute of Medicine/IOM (now the National Academy of Medicine/NAM) proposed <u>clinical diagnostic criteria</u> in 2015 based on the common core symptoms of ME/CFS*.
- The IOM/NAM report is readily available: https://pubmed.ncbi.nlm.nih.gov/25695122/











Long COVID and Fatiguing Illness Recovery Program Dashboard



8472 Attendances 3241 Attendees

72

Sessions

52 Countries

LC&FIRP – Research Design



Emerging Themes: Clinician Perspective Challenges:

- Complex patients, many with loss, grief, medical trauma
- Overwhelming diversity of clinical symptoms across body systems
- 4- vs. 12-week time threshold; many patients recover before 12 weeks
- Documentation of initial triggering infection not always available
- Low clinician understanding/awareness of 'neglected' co-morbid syndromes: MCAS, Ehlers-Danlos syndrome, POTS/dysautonomia, SIBO, 'brain fog'
- Challenges of providing comprehensive, compassionate care in 20-minute visit and addressing difficult social determinants/financial barriers
- Some providers/specialists incredulous of diagnosis
- Limited therapeutic toolbox
- Must develop comfort in off-label use and limited evidence base
- Limited support so clinician often takes on advocate role

Emerging Themes: Patient Perspective

Challenges:

- Not enough 'Long COVID-informed' providers
- Difficult/impossible to navigate medical system; referred from specialist to specialist
- Medical trauma and 'gaslighting' by incredulous providers
- Grief, loss of function, acceptance of new limitations
- Little to no support with ADLs/iADLs making daily life difficult/impossible
- Navigating loss of income/reduced work. Hard to get disability benefits or job accommodations with limited community support
- Absence of approved/well-studied interventions
- Vulnerable to unproven, expensive diagnostic/therapeutic products

Emerging Best Practices

Clinician perspective:

- Naming & acknowledging the diagnosis
- Empathy, education, understanding
- Early deployment of self-management strategies: Pacing, activity modification, home support for ADLs/iADLs, sleep hygiene; (fitbit deployment)
- Symptom-targeted interventions (low-dose naltrexone, anti-histamines, cromolyn)
- Patient Navigation

Patient Perspective:

- Online grassroots/social media communities for info-sharing, emotional support
 - Sharing anecdotal therapeutic interventions
 - Awareness of and encouraging participation in clinical trials
 - Patient-led research
 - Peer learning exchange on how to navigate new normal, benefits, medical care access
- Centering lived experience: including patient perspective in policy meetings, provider education, conference, press coverage
- Increasing public awareness of long COVID, ME/CFS
- Coordination of care by competent, compassionate PCP + care coordinator/navigator

Lessons Learned from ME/CFS

- Legitimacy for skeptical clinicians
 - 2015 IOM/National Academies Report
 - US ME/CFS Clinician Coalition
 - Consensus Recommendations
 - ICD-10 code
- Simple straightforward diagnostic criteria
- Normative professional guidance
- CDC, IOM, NASEM educational materials
- Requires patient-centered model of care with patient voice included in policy, education, programs
- Caution with exercise-focused research or recommendations



Check for up

Considerations for Long COVID Definition

- Overlap of ME/CFS and Long COVID may be amenable to overarching 'post-infectious fatiguing illness' diagnosis
- Recovery does occur in 4–12-week window
 - Definition should allow for 'possible Long COVID' definition after 4 weeks
 - Exclusive 12-week definition would create challenges/delays for disability, work accommodations
- Clinical presentation often sorts into patients with known/documented trigger vs. unknown/undocumented trigger
- Definition should be sensitive to demonstrable organ-specific post-COVID sequelae (e.g. from ICU/severe disease, such as pulmonary fibrosis, thromboembolic complications)

Summary

- Role of PCPs is essential for education, implementation of Long COVID definition
- Ongoing need for clinician education (primary care and specialty)
 - Basics of pathophysiology of Long COVID/PCC, ME/CFS
 - Emerging literature from RECOVER and other ongoing trials
 - Patient perspective
- Current working definition too broad to be practically useful and widely implemented
- 4-week vs. 12-week definition could have unintended consequences
- Must adapt definition to current understanding of pathophysiology
- May be beneficial to add modifiers: cognitive, autonomic, fatigue, MCAS/hypermobility syndromes, known/documented trigger vs. unknown
- Long COVID definition should be first step in comprehensive approach to influence systems of care to better respond to complex patient needs

Questions?