Re-Defining "Long COVID"

Perspectives from a Frontline "Long COVID" Specialist, Primary Care Physician, and Long COVID Researcher

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NASEM Meeting of the Committee on Examining the Working Definition for Long COVID
5/12/2023

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Outline

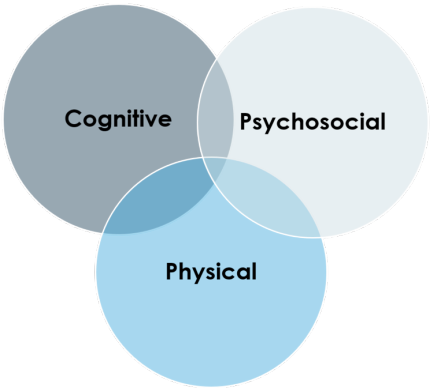
- Post-COVID Rehabilitation and Recovery Clinic
  - Common signs and symptoms
  - Diagnostic criteria used to screen patients
  - Treatments provided
  - Challenges related to diagnosis and treatment
  - Use of a Long COVID definition
- Primary care
  - More challenges

UW Post-COVID Rehabilitation and Recovery Clinic: *Patient-Centered Approach*

"We Focus patients on a path to recovery rather than a path to long-lasting disablement"

Thousands of patients seen since May 2020
Demand for clinic services continues to grow

- **150 new patients and 200+ return visits/month**
- **Referrals from Washington, Wyoming, Alaska, Montana, Idaho**



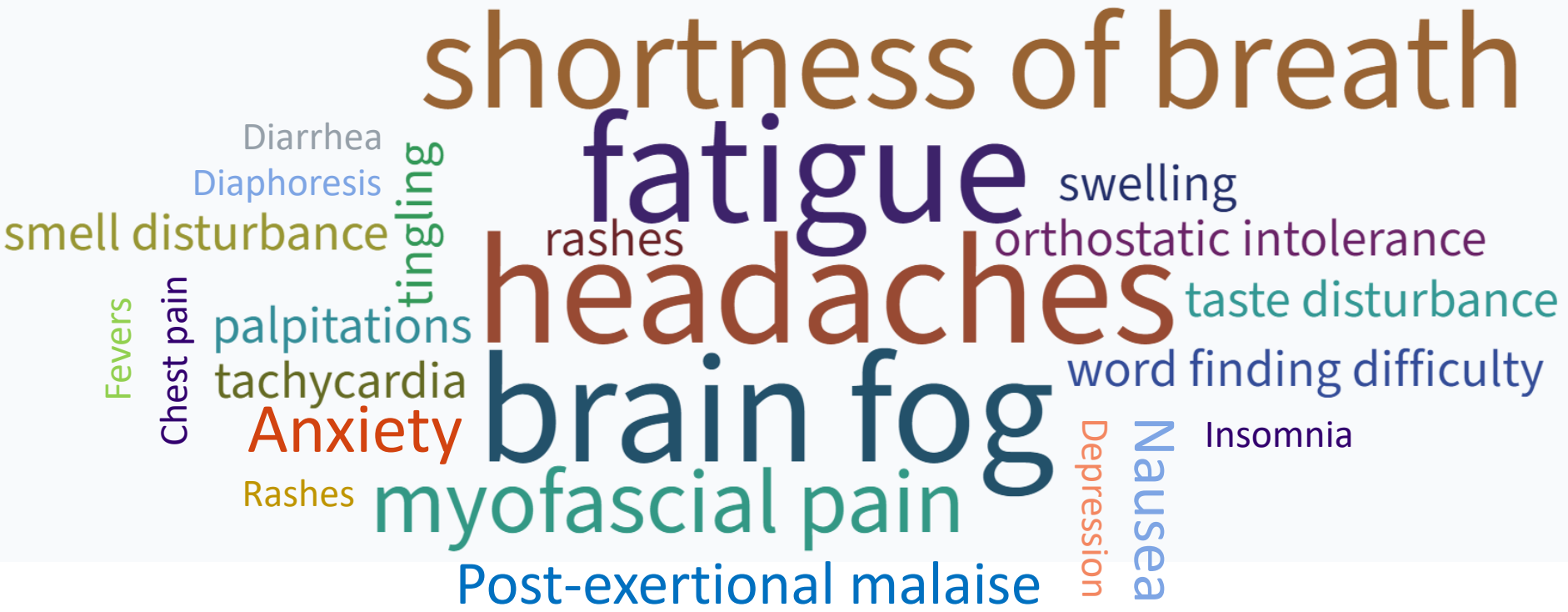
Core Clinic Team:

- 10 clinicians (5 PM&R, 2 FM, 2 IM, 1 Neurology)

Leadership Team:

- Executive Director: Janna Friedly MD, MPH
- PM&R Medical Director: Julie Hodapp MD
- GIM Medical Directors: Jessica Bender, MD, MPH; Anita Chopra, MD
- Primary Care/FM Medical Director: Nikki Gentile, MD, PhD

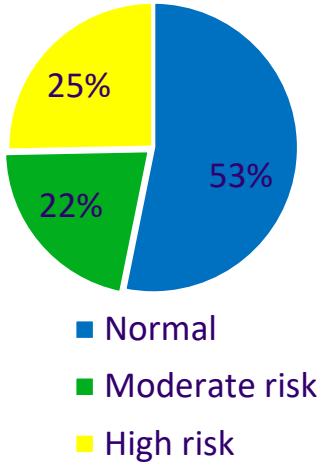
Common Signs and Symptoms



…AND MANY MORE!

Negative Impacts Seen at UW

- **Decreased function and quality of life**
- **42% unable to work post-COVID vs 2.6% pre-infection**
  - Financial hardship
  - Increased stress, anxiety, depression
  - Family strain
- **Pediatric patients can experience similar symptoms negatively impacting:**
  - School attendance
  - Participation in organized sports and hobbies
  - Mental health



UW Concerns About Pain Scale (n=707) ~75% of patients with Long COVID are at moderate/high risk of developing prolonged pain and disability.

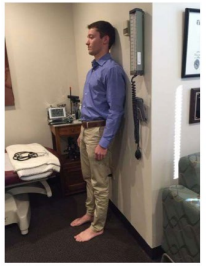
Caveats with “Long COVID” (LC)

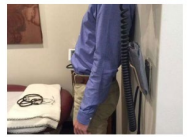
- **Underlying comorbid conditions complicate LC**
- **Many patients referred to us for “Long COVID” are found to have new onset, or worsening:**
  - Endocrine issues: Diabetes, thyroid disease, menopause
  - Sleep issues: Sleep apnea, Poor sleep hygiene
  - Nutrition deficiencies: Iron deficiency, B12 deficiency, Vitamin D deficiency (Seattle…)
  - Musculoskeletal concerns: Fibromyalgia, gout, deconditioning
  - Autoimmune conditions: PMR, or worsening of underlying autoimmune disease (e.g., lupus, RA, etc.)
  - Psychological concerns: Depression, anxiety, PTSD, social stress, Substance use disorders
  - Medication side effects
  - Other infections: viral illnesses, urinary tract infection, osteomyelitis
  - Post-vaccine reaction
  - Cardiac conditions: CHF
- **Above diagnoses may be completely unrelated → if treatment for above dx does not result in significant improvement in symptoms, there may be a concurrent Long COVID diagnosis given**

Diagnostic Criteria

Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION

- **Screening / Triaging of referrals (pre-consult)**
  - Documented, or presumed COVID >3 months ago
  - Severity of symptoms → impact on daily function
- **Work-up (consult)**
  - Patient-reported outcomes: PROMIS-29, PHQ-9, GAD-7
  - Vitals and physical exam (often unremarkable)
  - Orthostatic vitals +/- 10-minute NASA Lean
    - If equivocal results → formal autonomic testing
  - Basic labs: CBC w/ diff, CMP, HbA1c, TSH w/ reflex T4, ferritin/iron panel
    - Done to rule out other medical issues
    - Additional labs only if indicated: e.g., CRP, ESR, D-dimer, troponin, ANA, cortisol, vit D
  - If indicated: EKG, echocardiogram, cardiac monitoring, chest Xray, neuropsychiatric testing





Orthostatic Vital Signs/The 10-Minute NASA Lean Test

	Blood Pressure (BP)		Heart Rate	
	Systolic	Diastolic	bpm	Comments/Symptoms
Supine 1 minute				
Supine 2 minute				
Standing 0 minute				
Standing 1 minute				
Standing 2 minute				
Standing 3 minute				
Standing 4 minute				
Standing 5 minute				
Standing 6 minute				
Standing 7 minute				
Standing 8 minute				
Standing 9 minute				
Standing 10 minute				

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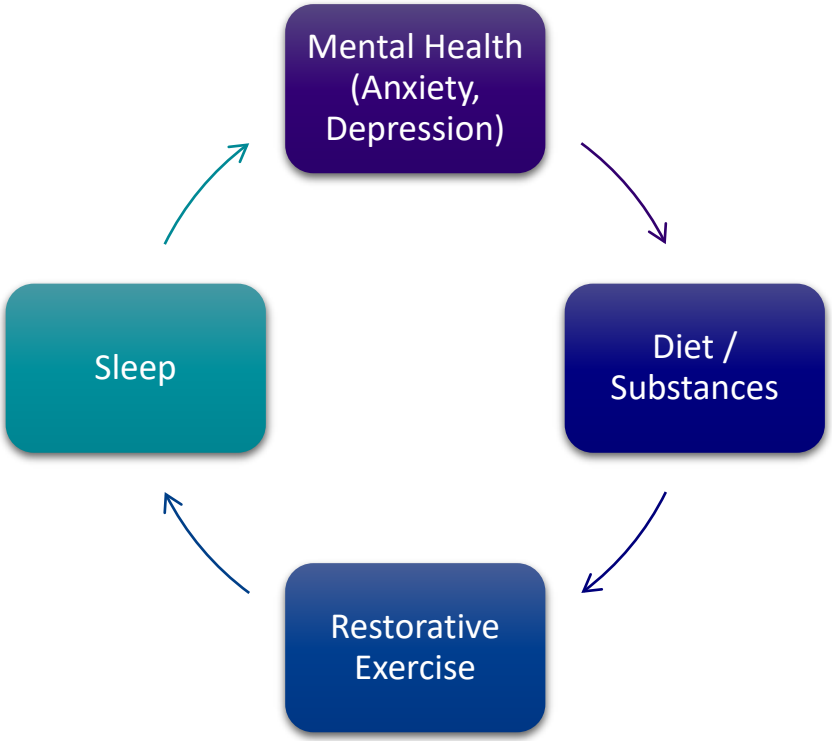
Treatments:
Focused Four

- Likely a major contributor to Fatigue
- Assessment: PROMIS Sleep, STOP-Bang
- Sleep hygiene
- Stress / Mental Health
- Diet & Exercise
- Consider Cognitive behavioral therapy for insomnia (CBT-I)
- Consider Short-term pharmacotherapy, if indicated

- Rehab psychology individual, or group visits
- Integrative behavioral health model



- Dietary needs vary
- Substances (Significant sleep and mental health impacts)
  - Low or no alcohol
  - Avoid Caffeine after noon, limit overall intake
  - Address other substance dependence

- Physical Therapy → using RPE scale, SpO2 & HR monitoring, breathing exercises (basic pulmonary rehab)

Other Treatments Considered

Focused on symptom management

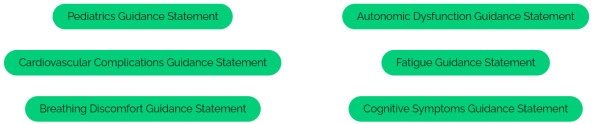
- Massage therapy
- Acupuncture – pain, fatigue, GI symptoms
- Speech therapy – brain fog, concentration
- Medications:
  - NSAIDs, Tylenol (pain)
  - H1+H2 blockers (GI and allergy sx, other)
  - SSRI/SNRIs (depression, anxiety, pain, cognition)
  - Beta-blockers (autonomic dysfunction, inappropriate tachycardia)
  - Low dose naltrexone (pain, brain fog)
    - Expensive, ?insurance coverage, compounded
  - Many others!

PASC Collaborative Resource

aapm&r

Published Guidance

The collaborative is working to publish guidance on a rolling basis. Writing groups are working within a consensus process with 3 waves. All published guidance will be linked here as it becomes available.



https://www.aapmr.org/members-publications/covid-19/pasc-guidance

Challenges: *Diagnosis and Treatment*

- No definitive testing or approved treatments.
- Inequities in research - Not able to participate in clinical trials without documented positive COVID test.
- Not fully recognized by insurance and worker's compensation entities
  - Long COVID impacts daily functioning and ability to work
  - Denials may lead to delayed work-ups, initiation of therapies, and return to work
  - Stressful for patients and clinicians
  - Slowly improving
- Difficulty obtaining school, or work accommodations, disability.

Challenges: *The "Long COVID" Term*

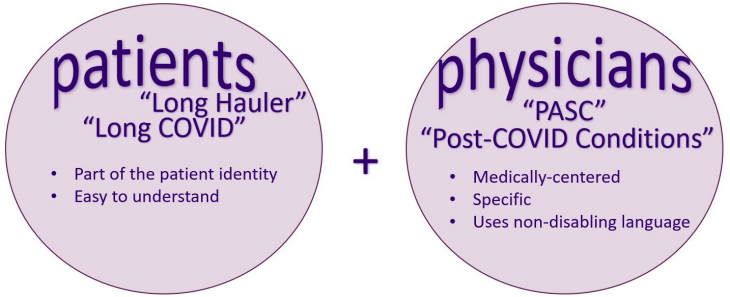
- **Lack of a clear definition and inconsistent timing from acute illness to diagnosis of Long COVID (i.e., 4-12 weeks)**
  - Patients seek many tests in search of objective findings to support diagnosis → Overuse of tests, feeds into "disability convictions"
  - Many recover in the general post-viral period, between 1-3 months
- **Current definitions influenced by symptoms reported by patients seen in clinics and enrolling in research studies**
  - Inequities in access to care → Lack of understanding of how LC affects underrepresented populations
  - Cultural factors may impact understanding and perception of symptoms
- **Patients feel that "Long COVID" is permanent - *But how long is long?***
    - We prefer to avoid "long hauler," or "long haul COVID"
      - Shapes identity, impacts recovery → "strong disability conviction"

Preferred Terminology at UW

"We Focus patients on a path to recovery rather than a path to long-lasting disablement"

- Terms commonly used in our clinic
  - Post-acute sequelae of COVID-19 (PASC) – direct effects of the virus
    - Preferred, more specific → similar to diagnosis of exclusion
  - Post-viral syndrome – non-specific
    - Does not shape identity
    - "Persisting symptoms after COVID"
  - Post-COVID conditions – indirect and direct effects
    - Less preferred given too broad, not specific enough, public considers dx at 4+ weeks
- While formal, these terms are not patient-centered and are not equal
- We are strong proponents of re-defining the terms

Re-Defining Long COVID



- Suggestions/Considerations:
  - Implement as a diagnosis of exclusion
  - Use the diagnosis only AFTER the general post-viral period
    - i.e., >2 months, (preferred 3 months) after acute illness
  - Address if new onset, or relapse
  - Remove any disabling connotations → allow for possibility of recovery
  - Remove inequitable qualifiers (e.g., "since COVID-like symptoms" instead of "since positive COVID test")
  - **Use sub-groups when appropriate (e.g., fatigue sub-type, autonomic sub-type, musculoskeletal sub-type)**
    - Papers emerging on clustering analyses

Additional Points: *Primary Care Perspective*

- **Keep diagnostic criteria simple**
  - "Complex diagnostic criteria can feel like gatekeeping" → unnecessary referrals
- Requests for additional training to feel more comfortable managing Long COVID
  - Patients often request to see a "long COVID" specialist
- Need more staff assistance to address between visit care needs
  - Patients with Long COVID frequently send messages, admin needs (e.g., FMLA)
- Need longer visit lengths as time allotted in primary care does not match complexity of condition (Primary care visits usually 15-20 min)
- Boundary setting: Balance institutional $$$ with patient expectations/needs and clinician well-being

THANK YOU!

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