Rehabilitation of Post-acute COVID-19 Syndrome

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What are we treating?

Long COVID and/or Post-Acute Sequelae of COVID (PASC):
Any persistent (>4 weeks from initial infection) symptom or set of symptoms that is related to acute COVID-19 infection
What are we treating?

Post-acute sequelae of COVID (PASC)/Long COVID

Persistent symptoms with an explicable, medical cause
- Pulmonary fibrosis
- Pericarditis/Myocarditis
- Skin issues
- Many other sequelae...

Patients with medically unexplained physical symptoms
- Post-Acute COVID-19 Syndrome (PACS)
- Post-ICU Syndrome (PICS)
What are we treating?

PASC/Long COVID

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Pericarditis/Myocarditis
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Patients with medically unexplained physical symptoms

Post-Acute COVID-19 Syndrome (PACS)
Post-ICU Syndrome (PICS)
Why does this matter?

Post-acute sequelae of COVID (PASC)/Long COVID

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Why does this matter? Treating PURE, symptomatic pulmonary fibrosis

Pulmonary Fibrosis

Medical management with bronchodilators and other symptom controllers

Monitoring progress with exercise tolerance and lung imaging

Pulmonary rehabilitation

Airway clearance techniques

Resistance training

Aerobic exercise (using SpO2 and heart rate as a guide)
Why does this matter?

• People with post-acute Pulmonary Fibrosis from their acute COVID-19 infection **HAVE LONG COVID**

• You *can* successfully treat pulmonary fibrosis with pulmonary rehabilitation

• You *cannot* successfully treat all Long COVID with pulmonary rehabilitation

• **Some** (not all) cases of Long COVID *will* respond to pulmonary rehabilitation
What are we treating (Part 2)?

The medical community has a pretty good handle on how to manage these.

Persistent symptoms with an explicable, medical cause
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- Many other sequelae...

Patients with medically unexplained physical symptoms
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What are we treating (Part 2)?

PASC/Long COVID

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Patients with medically unexplained physical symptoms
- Post-Acute COVID-19 Syndrome (PACS)
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The medical community traditionally has a terrible track record managing these conditions.
What are we treating (Part 2)?

PASC/Long COVID

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- Many other sequelae...

Patients with medically unexplained physical symptoms

- Post-Acute COVID-19 Syndrome (PACS)
- Post-ICU Syndrome (PICS)
What are we treating...TODAY?

PASC/Long COVID

Persistent symptoms with an explicable, medical cause

Patients with medically unexplained physical symptoms

Pulmonary fibrosis
Pericarditis/Myocarditis
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Post-Acute COVID-19 Syndrome (PACS)

Post-ICU Syndrome (PICS)
What are we treating...TODAY? (Disclaimer)

Patients with medically unexplained physical symptoms

Post-Acute COVID-19 Syndrome (PACS)

PACS A  PACS B  PACS C  PACS ...
PACS: What does it look like?
PACS – Rough Demographics (from >200 cases with a detailed evaluation)

- **Gender**
  - Female: 71%
  - Male: 28%
  - Non-binary: 1%

- **Median age**: 43 (12 - 78)

- **BMI**: 24 (16 - 44)

- **Hospitalized for COVID**: 4%

- **COVID “status”**:  
  - PCR/Antibody positive: 55%
  - Presumptive positive using WHO guidelines: 45%

- **Race/Ethnicity**
  - White: 88%
  - Asian: 6%
  - Black/African American: 2%
  - American Indian/American Native: 1%
  - Native Hawaiian/Pacific Islander: 0%
  - Other: 7%
  - Hispanic/Latinx: 10%

- **Notable Comorbidities**:
  - Previous Cancer (all types): 26%
  - Asthma: 24%
  - Anxiety: 13%
  - Depression: 9%
  - Hypertension: 9%
PACS – Symptom presentation

Tabacof et al, 2020: https://www.medrxiv.org/content/10.1101/2020.11.04.20226126v1
Know your symptoms!

**Fatigue**
- A feeling of weariness, tiredness, or lack of energy
- Can be physical, emotional or cognitive
- Persistent and debilitating

**Exercise Intolerance**
- Inability to engage in exercise
- Immediate onset: patient must stop during activity due to symptoms

**Post-exertional Symptom Exacerbation**
- Severe symptom flairs as a result of exertion
- Exertion can be physical, cognitive or emotional
- Delayed-onset: exertion can trigger symptoms days later
PACS – Most common symptom triggers

• Physical or cognitive exertion (86%)
• Stress (69%)
• Dehydration (49%)
• Weather changes (37%)
• Consuming large meals (28%)
• Premenstrual period (22%)
• Alcohol consumption (22%)
PACS – Impact on participation

- 40% of patients reported moderate to severe shortness of breath (MRC Breathlessness Scale)
- 78% of patients reported problematic fatigue (Fatigue Severity Score)
- 63% of patients scored for at least mild cognitive impairment (Neuro-Qol)
- 62% of patients have had to change their employment status as a result of their symptoms

Tabacof et al, (in press)
PACS: How do we treat it?
Clinicians: know your history

- **Be aware** that there is a long and storied history of clinicians gaslighting patients presenting with post-viral syndromes and other conditions with invisible symptoms.
- **Understand** that physicians have told the ME/CFS community “all you need is exercise and positive thoughts” for decades.
- **Acknowledge** that these approaches have consistently led to harm: worsened symptoms and increased disability.
Current care pathway for patients with PACS

**MYMEE**

- Initial evaluation (physician)
- Cardiac clearance (EKG/Echo)
- Begin work on behavioral strategies to get symptom attacks under control
- Referral to specialties care (Nutrition, Cognitive rehab, Neuropsychology, etc)
- Referral to breathwork coaching for prehab
- Referral to physical therapy for Autonomic Conditioning Therapy
Autonomic Conditioning Therapy

• A novel autonomic rehabilitation program for PACS patients

• The design has been based on existing, successful rehabilitation programs for dysautonomia with specific customizations for PACS

• To date, we have trained >700 clinicians in the United States on how to run the program

• We have data from over two hundred patients to suggest that autonomic rehabilitation appears to work in easing PACS symptoms
Autonomic Conditioning Therapy Eases Symptoms of PACS and improves function

10MWT Time: Baseline vs. Follow-up

6MWT Distance: Baseline vs. Follow-up

Number of reported symptoms: Baseline vs. Follow-up

Fatigue Severity: Baseline vs. Follow-up
Is it “working”?  

- What we are presenting is that **careful and skilled** autonomic rehabilitation appears to ease symptoms of Long COVID and increase function in patients.  
- It requires intensive rehabilitation over a long period of time.  
- We have observed relapses in patients post-discharge.
DISCLAIMER: We are still discovering all of the ways that Long COVID affects the body. There will be clusters of patients that are non-responsive to our approaches.

Remember this slide?

Post-Acute COVID-19 Syndrome (PACS)

- PACS A
- PACS B
- PACS C
- PACS ...


PACS Rehabilitation

- Behavioral and trigger management
- Breathwork
- Medical Management
- Pacing
- Autonomic Rehabilitation as tolerated
Future: Understanding the pathophysiology of Long COVID
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