Long Covid – Still a thing?

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Disclosure

I have no actual or potential conflict of interest in relation to any product or service mentioned in this program or presentation.

Agenda

1. Explain the Definition and description of Long-Covid
2. Define those at higher risk of developing Long-Covid
3. Be able to identify the symptoms and signs of Long Covid
4. Learn the current treatment and future prospective treatment
5. Explain the long-term impact on QOL mentally & physically
6. Review how to integrate knowledge to impact the work of case managers and nurses.

Paul 35yo, Urban Planner. Married father of 2

- **Prior** to CV-19: Rode his bike to work daily, spent weekends cycling
- **SX now**: can barely get through a light walk

- post-exertional malaise, intense fatigue

-Unrefreshed sleep, fatigue & dysautonomia

-@ impossible to share in household duties with wife with 2 sons 6,8yrs old in the house

John 41yr old, Richmond VA

- Dx with COVID-19 in May 2022
- Acute infection was mild
- Everyone in his family recovered
- **His Sx**: Heavy fatigue that never resolved “When I wake up in the morning feels like I haven’t gone to sleep at all”

Erica, 40 yo @ Western Pennsylvania

- Felt sick since contracting COVID 11/2020
- Feels too sick to work
- spent much of the last 4 yrs sitting on her beige couch, often curled up under an electric blanket
- Can't play sports w son or go to games
- **SX:**
  - "My blood flow now sucks, so my hands and my feet are freezing. Even if I'm sweating my toes are cold"
  - Gets frequent hives and migraines.
  - her tongue is constantly swollen & dry.

Health News Florida Jan 10, 2025

Definition & Description

Long-COVID name ??

- ❑ Post-Acute Sequelae of COVID (PASC)
- ❑ Long-haul COVID
- ❑ Post COVID condition (PCC)
- ❑ Chronic COVID

Long-COVID definition ??

Formal name: Post-Acute Sequelae of COVID

The definition of long COVID is ambiguous.

'Defined' as:

➔a chronic condition that occurs after SARS-CoV-2 hyperinflammatory infection state

➔is present for at least 3 months.

Long COVID includes a wide range of symptoms or conditions that may improve, worsen, or be ongoing.

- It is a Symptom-driven disease

What is Long Covid (per CDC)

- Anyone who had a SARS-CoV-2 infection, the virus that causes COVID-19, can experience Long COVID, including children.

- can include a wide range of ongoing symptoms and conditions (>200)

- can last weeks, months, or even years after COVID-19 illness

- is a serious illness that can result in chronic conditions

- Each time a person is re-infected with SARS-CoV-2, they have a risk of developing Long COVID.

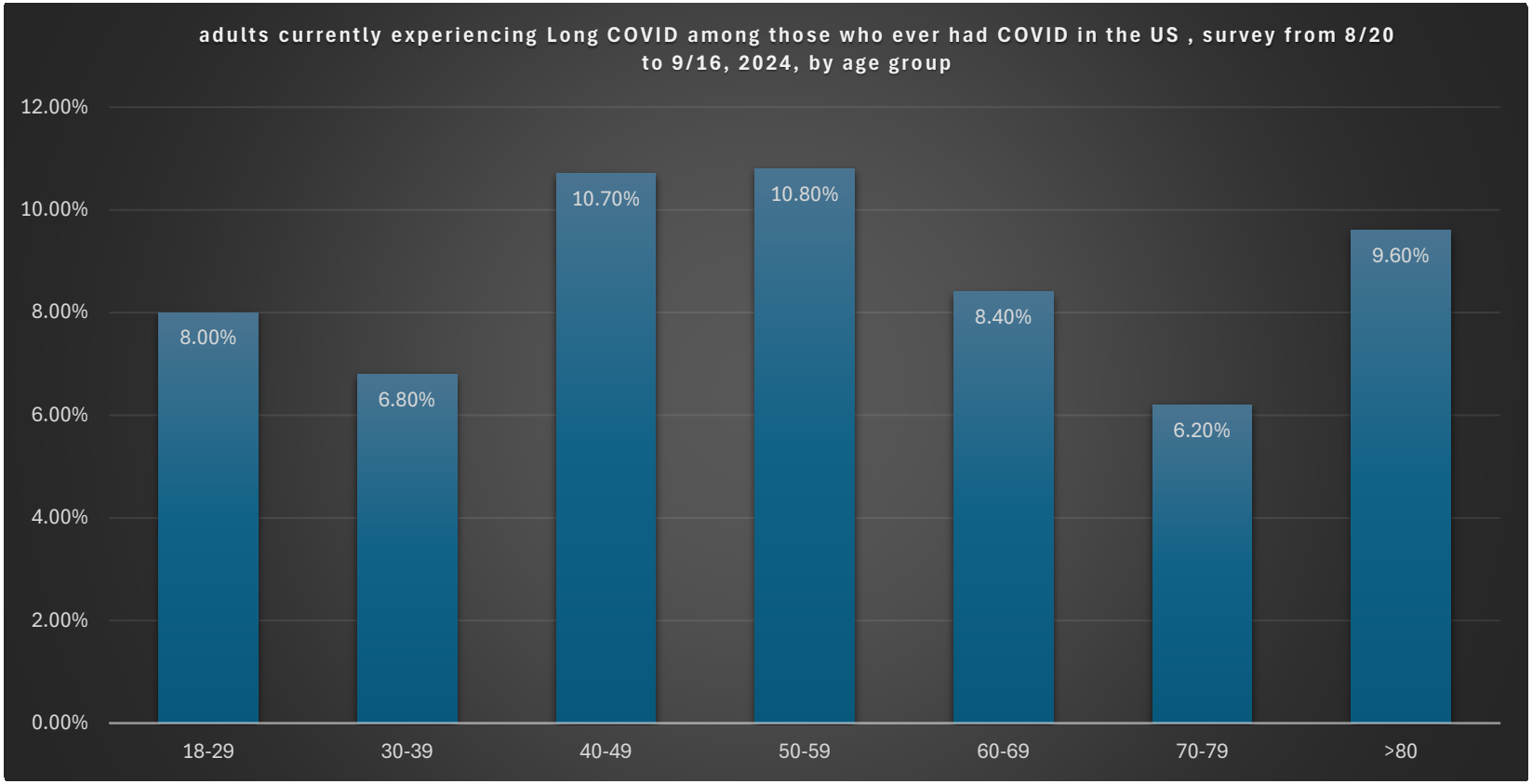
What is the cause of Long-COVID

- Numerous causes of long COVID have been posited.
  - 1. Among them are *virus-induced changes* in our resident gut bacteria; residual inflammatory overdrive;
  - 2. COVID-spurred human Antigen *autoimmunity* by molecular mimicry;
  - 3. the *reawakening of other infectious viruses* that have woven themselves into our genomes and remained dormant, only to emerge when our SARS-CoV-2-preoccupied or exhausted immune systems let their guard down.
  - 4.*Hidden reservoirs of SARS-CoV2* persist in the body
  - 5. SARS-Co2 disrupts the gut integrity***: (causes post-infectious IBS-like symptom)
  - 6. SARS-CoV2 causes *endothelial dysfunction ** / Platelet dysfunction/Micro-vascular Dysfunction*

Recent (as of June 2024) evidence has suggested Long-COVID is primarily an autonomic nervous system disorder – *Linda McAlpine MD, Yale Sch of Medicine NeuroCOVID Clinic*

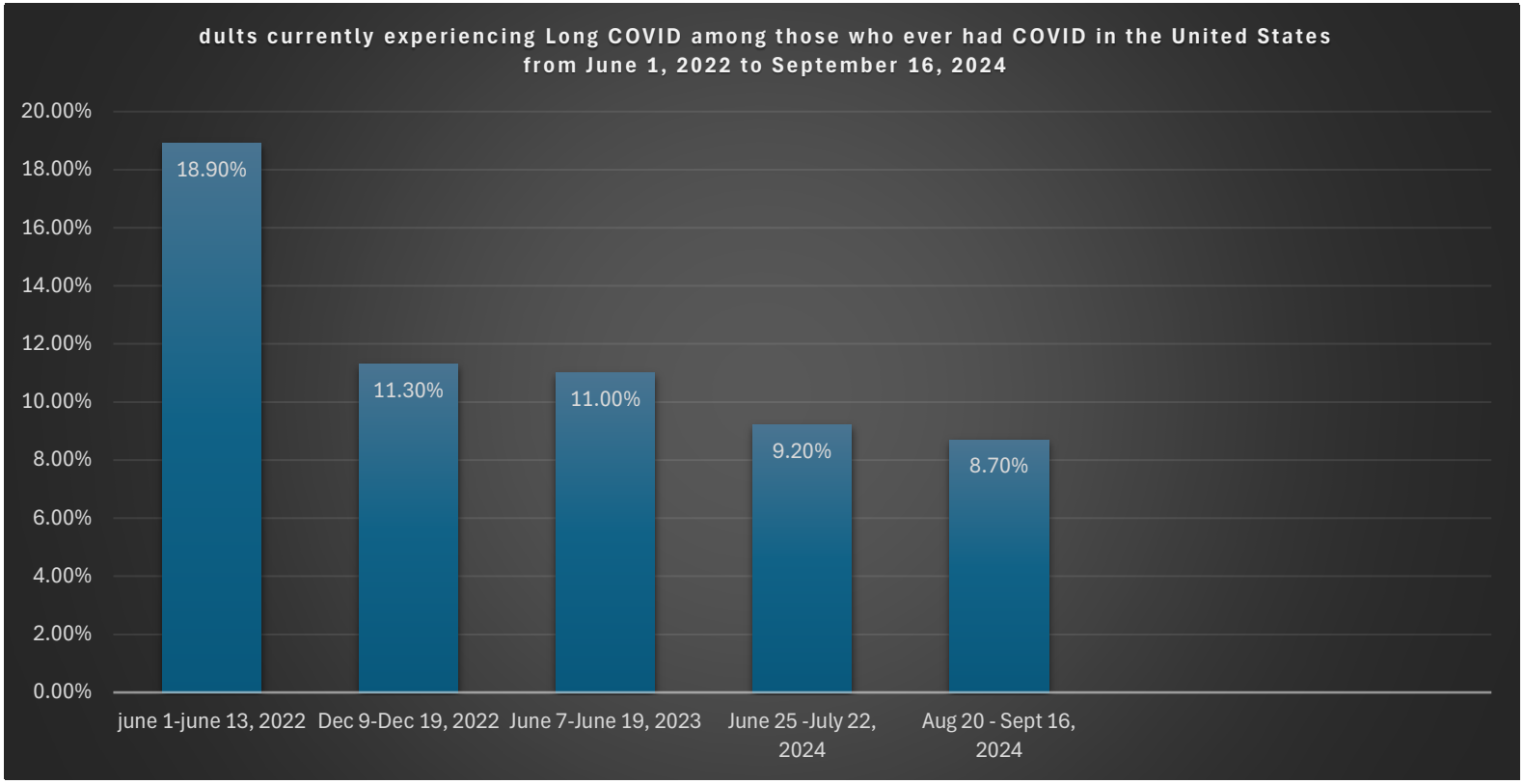
Who is most at risk?

Adults currently experiencing Long COVID among those who ever had COVID in the United States from August 20 to September 16, 2024, by age group



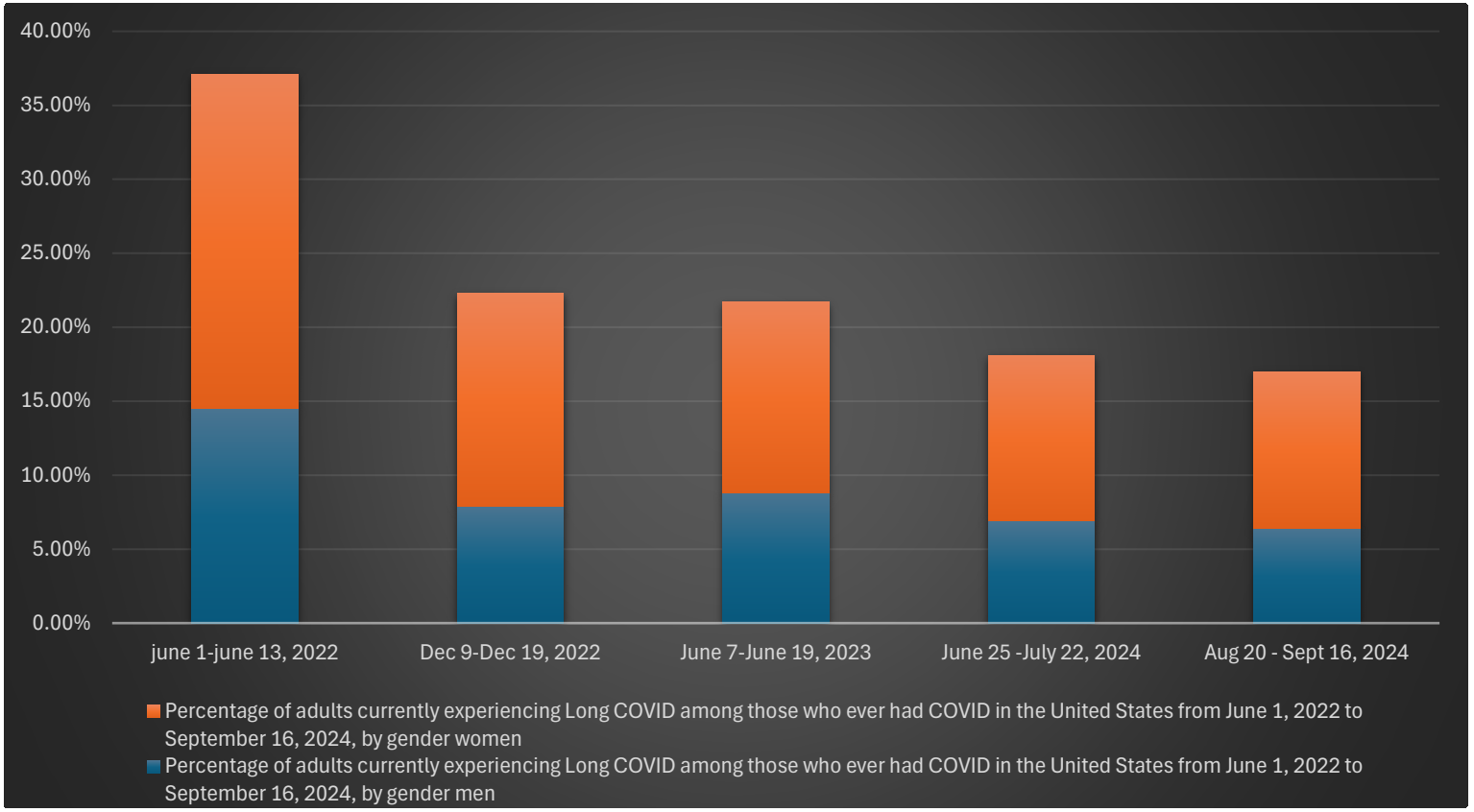
Source: CDC Household Pulse Survey 2022-2024 of adults >18yo, US Census Bureau, Release date Oct 2024. -The Household Pulse Survey - NCHS, the Census Bureau, and other federal statistical agencies are considered the preeminent source of the nation's most important benchmark surveys. It was designed to go into the field quickly, to be administered via the web, and to disseminate data in near real-time, providing data users with information they can use now to help ease the burden on American households and expedite post-pandemic recovery. The Census Bureau is fielding the Household Pulse Survey as a demonstration project, with data released as part of its Experimental Statistical Products Series. Confidence intervals included in the tables on this page only reflect the potential for sampling error. Nonsampling errors can also occur and are more likely for surveys that are implemented quickly, achieve low response rates, and rely on online response..

Adults currently experiencing Long COVID among those who ever had COVID in the United States from June 1, 2022 to September 16, 2024



Source: CDC Household Pulse Survey 2022 – 2024 of adults >18yo, US Census Bureau, Release date Oct 2024

Percentage of adults by gender currently experiencing Long COVID among those who ever had COVID in the US from June 1, 2022 to September 16, 2024.



Source: CDC Household Pulse Survey 2022 – 2024 of adults >18yo, US Census Bureau, Release date Oct 2024

Statistics & Prevalence

- According to the CDC (Centers for Disease control and prevention) of the total population who have long-COVID syndrome:
  - 6.9% of adults aged 18 to 34 years
  - 8.9% of adults aged 35 to 49 years
  - 4.1% of older adults age greater than 65 years old

According to Stastica

- 80% :- of adults in US w Long –COVID who reported any activity limitations
- 85.1% :- of adults in the US each 18 to 29 with Long-COVID reported any activity limitations

Who is at risk?

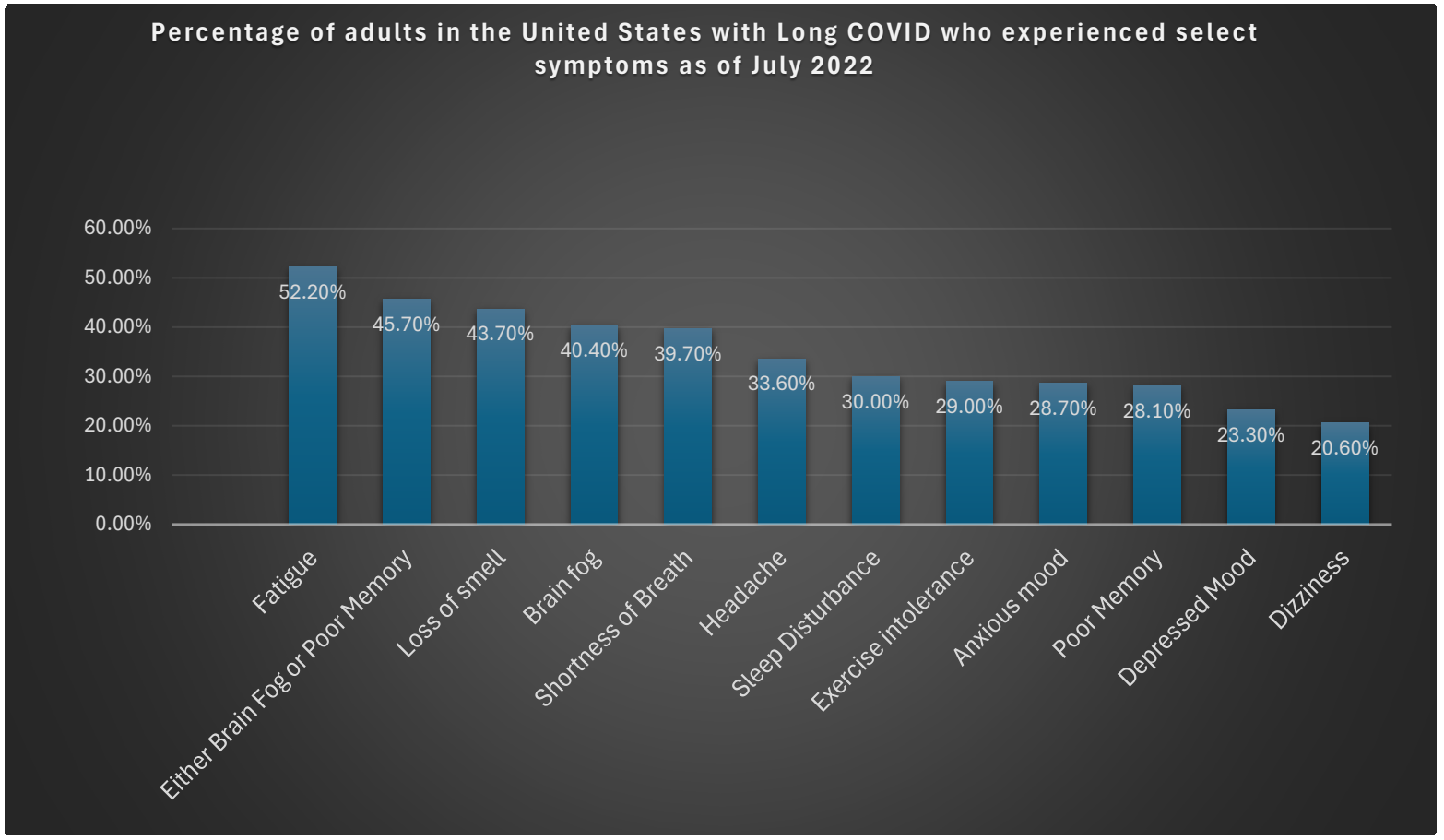
- Hispanic and Latino people
- Women and adults with pre-existing chronic illness (took longer >20d, even >90d to recover)
- Women 30-50yo regardless of presence of chronic ds.**
- People with >/ 3 COVID-19 infections are 2.6x more likely to develop Long-COVID
- People s/p more severe COVID-19 illness, esp s/p hospitalized or ICU
- People with underlying health conditions and adults >/65 yo
- COVID-19 Unvaccinated or under-vaccinated
- Male sex was the strongest predictive factor for Long-covid related *cognitive dysfunction and cardiopulmonary complications* in follow up. (Medscape)
- Persons with prior history of Cardiovascular disease, ie have had a heart attack or stroke (Medscape)
- Young middle aged highest # affected due to volume of persons affected by CV-19** *Younger people with long COVID are generally underreported & undertreated*

What are the most common signs and Symptoms?

Most common signs & Sxs & Conditions?

- There **are >200** documented Symptoms related to Long-COVID (Moderna)
- symptoms and conditions can **emerge, persist, resolve, and reemerge** over weeks and months.
- symptoms and conditions can **range from mild to severe** (CDC)
- Can occur **after acute COVID-19 even with mild symptoms**
- Can develop **without knowing when infected, Asymptomatic or after SX relief/remission**
- Long COVID is **not contagious** and doesn't spread between people
- **Women 30-50yo** among the most susceptible to Long COVID & face a greater risk of autoimmune diseases in general
- Children - exhibit significantly higher rates of phsycological issues and depressive symptoms (less correlation seen with anxiety symptoms); more frequent somatic or psychological health complaints and lower health related quality of life than peers.

Percentage of adults in the United States with Long COVID who experienced select symptoms as of July 2022



Source: CDC Household Pulse Survey 2022 – 2024 of adults >18yo, US Census Bureau, Release date Oct 2024

Most common & less common Sx/Conditions

Other symptoms:

- Sleep problems.
- Shortness of breath.
- Cough.
- Headache.
- Fast or irregular heartbeat.
- Digestion problems, such as loose stools, constipation or bloating.
- “Relapse” ***

Diseases that may be diagnosed with Long-COVID:

- Heart disease.
- Mood disorders.
- Anxiety.
- Stroke or blood clots.
- Postural orthostatic tachycardia syndrome (POTS)
- Myalgic encephalomyelitis-chronic fatigue syndrome (ME-CFS)
- Mast cell activation syndrome.
- Fibromyalgia.
- Post-exertional malaise (PEM)**

Can you have a “Relapse”? YES!

- Many people who previously had Long-COVID have **developed recurring symptoms** after subsequent viral infections (not just from COVID but from the cold, flu, and other viral pathogens) – Yale Researchers
- “Long-COVID appears to be a chronic condition with few patients achieving full remission” according to a new Academy of Sciences report. The report concludes that Long COVID recovery can plateau at 6 to 12 months. They also note that 18 to 22% of people who have long COVID symptoms at five months are still ill at one year. ~ PolyBio Institute.
- Patients can “recover, or feel like they recovered, from Long-COVID until the next immune challenge - another COVID infection, flu infection, pregnancy, food poisoning- and experience a significant flare up of their initial COVID infection David Putrino PhD-PMR Mt Sanai HS in NYC”

What are the current and future treatments & suggestions?

Current treatments

Current medical treatments

- ***There is no Approved FDA drug to treat Long-COVID***
- Its unlikely that a single drug could cure everyone with long COVID.
- Finding a cure is complicated by realizing the disease likely has multiple underlying causes, different subtypes so the client different treatments

- **Convalescent Plasma** – outpatient early treatment
- **Paxlovid** -> not everyone will respond

Suggestions

- 1. **Avoid crowded indoor spaces-** Patients with known cardiovascular disease should avoid acute infection with COVID-19 eg.
- 2. updated **COVID-19 vaccine boosters** – *per CDC: COVID-19 vaccination is the best available tool to prevent Long COVID*

    - US CDC recommends Updated COVID vaccines for all >6months for 2024-2025 (regardless of prior vaccination status)
- 3. **Cognitive Rehabilitation (CR)** - linked to the concept of neuroplasticity whereby, through practice, the brain can create new neural connections, or strengthen existing ones
- **Long-COVID clinics**

Future treatments

BCG (Bacillus Calmette-Guerin) Vaccine - shown that BCG for an existing ailment may be superior to prophylaxis in healthy individuals.

- Protects against the development of Long-COVID if given during the active phase of CV-19
  - Hearing problems were less frequent at 6 months compared to placebo
  - Fewer issues with sleeping, concentration, memory and vision at 12 month

Source: Journal of Internal Medicine - Mehrsa Jalalizadeh & Keini Buosi, UroSc, State University of Campinas, Unicamp, Sao Paulo, Brazil

Future treatments- ? Off-label (Medscape)

1. **Plavix** and other blood thinners – to treat 'microclots' found in Long-COVID suffers.
2. Low dose **Naltrexone** - for fatigue
3. **Nicotine** patches - for fatigue
4. **Rapamycin** (macrolide) - for immune function (immunosupp & anti-proliferative properties)
5. **Triptans** - for headaches
6. **beta blockers** - for postural orthostatic tachycardia syndrome, dizziness
7. **Paxlovid** for 15 days- for viral persistence (Lingering virus Hypothesis)
8. **IVIg** (Immunoglobulin) and FcRn Inhibitors – for autoimmune function
9. **Ivabradine** (HCN Channel blocker)- for POTS** (Postural Orthostatic Tachycardia)
10. **Hyperbaric Chamber**
11. **(2) repurposed HIV antivirals** (Truvada and Maraviroc) – lingering virus
12. **Metformin** **** -
13. **Guanfacine** (Central acting alpha 2A-adrenergic receptor agonist) –
14. **Supplements:** for brain fog
    1. NAC(N-acetyl Cysteine) - **often used w Guanfacine*
    2. Mitochondrial Enhancement - Combination of Alpha-lipoic Acid +Vit C+ combo Vit B
    3. Vit D3 : may increase risk of severe COVID & delay recovery. Replace if low blood levels

Future treatments- ? Off-label (con'd)

Results of clinical trials aren't expected to be available until 2028

- Treatment is impacted by PCP unawareness and comfort with using off label and hurdles of insurance prior authorization
- "Without clinical trials, physicians specializing in treating long COVID must rely on hunches to guide their clinical decisions."- Dr Al-Aly, VA ST Louis HC system

Impact on quality of life – mentally & physically

Mental health impact

Mental health impact

- The most frequently reported mental health symptoms in children (under 18yo) are:
  - changes in mood,
  - fatigue,
  - sleep disorders,
  - cognitive symptoms (e.g., less concentration, learning difficulties, confusion, & memory loss), and headaches

- **Neurologic and psychiatric disorders** may endure persistent, long-term (< 1 yr after acute COVID-19 diagnosis) – SAMHSA
- Olfactory dysfunction, or loss of smell, may also **confer long-term cognitive** impairment risk **
- **Chronic common Dx**: Continued Chronic Fatigue, PTSD, depression, Panic disorders
- **Stigma*****– many are dismissed due to presumption by many that Long COVID is a psychosomatic condition

Long term residual effects

Long term residual effects

- New onset cardiovascular disease; - There's a clear link between CV-19 and CVD (Medscape)
- Can result in a disability.(CDC)
- Older individuals (who are usually sicker to start) had more severe symptoms (Scientific Reports)

Effect on Productivity & Quality of Life

- Recent study in *Scientific Reports*, researchers also found that younger **people aged 18 to 49**, were more likely to experience **symptoms that reduce their productivity and quality of life****.
- Report in *The Lancet Regional Health* found in this cohort 18-49yo:
  - 5.8% of patients with long COVID reported **occupational changes** (eg. Moving to part time or remote work)
  - 1.6% completely dropped out of the workforce

- Study from *Disability and Health Journal* found that patients with long COVID have significantly **higher rates of housing instability and financial concerns** (eg. Paying rent or mortgage)
- Full impact is yet unknown as this cohort 18-49yo, is generally underrepresented, acute COVID-19 symptoms were mild and they have fewer underlying conditions.
- Comprehensive care for long COVID can be **time consuming and expensive** draining resources.

Long Covid as a disability – per ADA

- It's important to note that under **The American with Disabilities Act (AADA)**, long covid is considered a disability as of July 2021.
- As long as it "substantially limits one or more major life activities" (*which can include a wide range of functional tasks such as caring for oneself, concentrating, sleeping, eating, and many others. Even if the functional impairment waxes and wanes, it can still be considered a disability)*
- CDC Does not require a blood test for the diagnosis of long COVID
- The ADA Diagnosis is at the discretion of the treating physician

- Patients often have struggles to access ADA resources:
  - 1. People not getting *work accommodations* needed which is an ADA violation
  - 2. *Claims being denied* because of lack of diagnostic testing to prove the patient has a condition (despite no diagnostics required)

What can the service coordinators and nurses do?

How can you help a Long-COVID member?

- ✓Encourage management of Long COVID using patient-centered approaches.- Focus on the most bothersome symptoms identified by the patient
- ✓validate the patients' symptoms , ask @ triggers
- ✓ connect patients to additional care, services, and supports, as appropriate.
- ✓set achievable patient care goals through shared decision-making and approach suggestions or suggested treatments by focusing on specific symptoms or conditions.
- ✓Know that objective laboratory or imaging findings should not be used as the only measure or assessment of a patient's well-being.
- ✓Optimize management of underlying medical conditions.
- ✓Encourage creating patient diaries and calendars to document changes in health conditions and symptom severity.
- ✓Refer for Behavioral health concerns - recognizing the psychological aspects is critical

ADVOCACY, RESOURCES & SUPPORT Gps

- Patient-led Research Collaborative
- Long-COVID Alliance
- Long-COVID Campaign
- Longhauler Advocacy Project (C19LAP)
- New York Health Foundation
- Genesis House
- Administration for Community Living (ACL)
- Post-COVID Kids Bavaria

- *Encourage minoritized groups to get into Long COVID studies***

References & Articles

References

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