“Long” Covid: Defining Symptoms, Treatments and Caregiver Supports

Renee Garrett, MSEd, CCC-SLP, CBIS

Introduction

“Long” covid is classified by many names including “long haul covid”, “prolonged covid illness” and “post-acute sequelae of covid-19”. No matter the label, the symptoms patients experience have lasting impacts on their quality of life, return to work and fatigue response. In addition, caregivers of patients experiencing prolonged symptoms are experiencing mental health disorders, physical and somatic symptoms. What disorders might SLPs see in their practices and what treatment implications might occur? How can we provide safe and effective therapy, education and care for both the patient and their caregivers? Let’s delve into functional and supportive ways we can care for our patients and their caregivers experiencing this life change, immediately.

* What is “long” covid
* Time frame
* Broad definition

How do symptoms present?

* Persistent symptoms beginning at the time of illness that do not resolve
* New symptoms following a “remission” period or after symptom relief
* Symptoms “evolve” (shortness of breath not present before)

Worsening of co-morbidities present at the time of illness onset

* Symptoms: new or persistent
* Cardiac symptoms: tachycardia
* Cough
* Chest pain
* Myalgia
* Paresthesia
* Cognitive decline
* Poor endurance
* Fatigue
* Insomnia
* Abdominal discomfort/gastrointestinal changes
* Inability to complete normal daily tasks
* Mood changes/depression
* Reproductive changes: male and female

Research estimates vary on prevalence (5-30%)

R.M.’s story

* 58 year old AAF
* Received both the vaccination and booster series
* Relevant co-morbidities: lifelong asthma; prolonged bronchitis in the immediate two months prior to covid infection
* No recall of first 3-4 days of being hospitalized
* At that time, she was on BiPap support
* Transitioned to HFNC with BiPap at night
* Went to SNF for rehab with 5L O2NC support

Week one at home

* Describes her role as a “traditional” wife
* She did all the housework and cooking prior to this
* Not able to cook
* Not able to clean
* Struggled to get dressed
* Fatigued
* Felt guilty and “stressed” about giving up tasks
* Poor activity tolerance

Symptoms that persisted

* Somewhat aware of deficits
* Cognition/memory deficits
* Memory deficits apparent in conversation
* Relies on external memory aids
* Uses a pill box for medications
* Driving: lost track of where she was going; lost car in parking lot
* SOB doing laundry
* Still experiences decreased activity tolerance at work and during community outings (trip to winery with family)

Fear of re-exposure remains

* While no masks are mandated at work, she still wears one
* Wears a mask for most community outings
* Coughed intermittently and increased SOB while we were on the phone
* Her PCP told her she “would never the same” and that she “needed to accept that”
* She remains on an alternative work schedule due to fatigue

Caregivers experience

* Husband: “He never said he was stressed, but I could see it.”
* Younger sister reported he struggled to comprehend the critical nature of her illness
* Son: “He depended on his friends for support. He was scared I was going to die.”
* Both sisters brought meals in the early days she returned home; she does not remember that.

Younger sister

What does the research say about caregivers?

“Caregiver burden”

* Increased somatic symptoms (headache, fatigue, body aches, etc.) increased the chances of a psychological or mood disorder
* Physical symptoms increased the length in which depression lingered
* (Ohayon & Schatzberg, 2003)
* “sustained” caregiving (think dementia caregivers) tended to have higher incidences of physical symptoms and exhaustion

Mental health

Physical health

What daily activities?

Health disparities

* Costs incurred
* According to Cutler (2022), costs associated with long covid estimate
* “2.6 trillion dollars”
* What about employer sponsored insurance?
* Financial impacts on care/long term illness

Barriers to care

Rahimi, Dastyar and Rafati, 2021

Caregiver stress:

“incarceration, lack of leisure time, lack of assistance from other family members, poor care knowledge, caregiver age, and guild over ignoring the patient’s complaints”

Positive experiences:

“feeling good about themselves, compassion satisfaction, learning new skills, and strengthening family relationships”

One interesting conclusion from the study

“The healthcare system should provide adequate information and financial support to patients’ families.”

Park’s research

National Alliance on Caregiving, 2020

“Caregivers continued to fare worse than noncaregivers in terms of mental health and fatigue, and long-term caregivers were more likely to report headache, body aches and abdominal discomfort than both short-term caregivers and noncaregivers, **even after adjusting for demographic, socioeconomic and preexisting health traits**.”

Treatment

PT/OT to address mobility, fatigue and ADLS

SLP: cognitive, but functional treatment

Caregiver education/community support

Functional activities

Making appointments

Grocery or “to do” lists

Keeping track of their own calendar (external visual supports)

* What tasks are important at work?
* Co-tx with PT to determine physical impacts on cognitive response (correct as well as latency)
* If you can, community outings!

Patient/Caregivers stories

References

* Caring for People with Post-COVID Conditions | CDC, retrieved from https://www.cdc.gov , January 2023.
* Cutler DM. The Costs of Long COVID. *JAMA Health Forum.* 2022;3(5):e221809. doi:10.1001/jamahealthforum.2022.1809
* Long COVID or Post-COVID Conditions | CDC, retrieved from https://www.cdc.gov , January 2023.
* National Academies of Sciences, Engineering, and Medicine. 2022. *Long COVID: Examining Long-Term Health Effects of COVID-19 and Implications for the Social Security Administration: Proceedings of a Workshop*. Washington, DC: The National Academies Press. https://doi.org/10.17226/26619.
* National Alliance on Caregiving. (2020). *Caregiving in the U.S. (May 2020 report).* Retrieved from https://www.caregiving.org/caregiving-in-the-us-2020/ , January 2023.
* Ohayon, M & Schatzburg, A. (2003). Using chronic pain to predict depressive morbidity in the general population. Archives of General Psychiatry, 60(1), 39-47. doi:10.1001/archpsych.60.1.39
* Park, S. S. (2021). Caregivers’ mental health and somatic symptoms during COVID-19. *The Journals of Gerontology: Series B*, *76*(4), e235-e240.
* Post-COVID Conditions: Information for Healthcare Providers (cdc.gov), retrieved from https://www.cdc.gov , January 2023.
* Rahimi, T., Dastyar, N., & Rafati, F. (2021). Experiences of family caregivers of patients with COVID-19. *BMC family practice*, *22*(1), 137. https://doi.org/10.1186/s12875-021-01489-7
* Sritharan, J. & Sritharan, A. (2020). Emerging mental health issues from the novel coronavirus (COVID-19) pandemic*. Journal of Health and Medical Sciences,* 3, 157-162. doi:10.31014/aior.1994.03.02.109
* United Nations (2020). *COVID-19 pandemic exposes global “frailties and inequalities”: UN deputy chief*. Retrieved from https://news.un.org/en/story/2020/05/1063022