Canadian Audiologist
The Official Publication of the Canadian Academy of Audiology

Labeling COVID-19's Long Term Effects—What's the Diagnosis?

Published January 19th, 2022

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Appeared in

Audiology Today January/February 2021

This article addresses and defines the language associated with COVID-19 and reports on the attempts being made to establish appropriate medical terminology as it pertains to COVID-19 patients who are still experiencing medical issues for weeks and even months after the diagnosis.

Since the beginning of the COVID-19 pandemic, the medical and non-medical literature, as well as social media, have been using descriptive terms that are describing the same problem but in

different ways.

Initially, we saw Corona virus, Novel Corona virus, SARS (Severe Acute Respiratory Syndrome), SARS-Co-V-2, (Severe Acute Respiratory Syndrome Coronavirus 2), COVID (an acronym for Corona Virus Disease) and COVID-19 (with the number 19 representing the year of the discovery). TABLE 1 is a summary of the definitions of disease related to COVID-19 (Katella, 2020).

We then saw new phrases and words appearing in the literature. We also heard various media outlets use these words in news stories and they became part of our daily conversations about the virus. These phrases and words included ‘super-spreader,’ ‘flattening the curve’ and ‘personal protective equipment.’

But several terms not found in the early COVID-19 literature emerged in the summer of 2020 that described COVID-19 survivors who continued to report new or exacerbated medical issues possibly related to the COVID-19 virus.

Some of these labels included *COVID long hauler, long COVID, chronic COVID syndrome, post-COVID syndrome* and the non-medical term *brain fog*.

TABLE 1. Corona virus-related definitions (Katella, 2020).

NAME	EXPLANATION
Coronavirus	A family of viruses, seven of which are known to infect people. They get their name from the crown-like spikes – coronas - that appear on the viruses under a microscope. **Coronaviruses** can cause dangerous illnesses such as *Severe Acute Respiratory Syndrome* (SARS) and Middle East Respiratory Syndrome (MERS).
SARS (Severe Acute Respiratory Syndrome)	A coronavirus, which first infected humans in 2002, that reached epidemic proportions before it was contained - there have been no outbreaks since 2003. SARS causes fever, headache, body aches, a dry cough, hypoxia (oxygen deficiency), and usually **pneumonia**. SARS CoV-2, a coronavirus virus first discovered in December 2019, causes the disease now known as COVID-19. COVID stands for **C**orona**VI**rus **D**isease and the 19 indicates its discovery in 2019.

SARS-CoV-2 (**S**evere **A**cute **R**espiratory **S**yndrome Coronavirus 2)	The new coronavirus that causes COVID-19; believed to have been started in animals and spread to humans. Animal-to-person spread was suspected in December among people who had a link to a large seafood and live animal market in Wuhan, China. While no one knows for sure how SARS-CoV-2 spread from an animal (and what type of animal) to a human, SARS-CoV-2 is a betacoronavirus, which means it originated in bats. The coronavirus SARS-CoV-2 causes **COVID-19**.
COVID-19 (**CO**rona**VI**rus **D**isease 2019) – see SARS	Symptoms include cough, fever, and shortness of breath. While the disease appears to cause mild to moderate illness in most people, in others it has caused life-threatening pneumonia and death.

History

The first time that a specific label was used identify a COVID-19 survivor who later developed other medical problems after treatment had been concluded was in the summer of 2020 (Cleveland Clinic, 2020). At first, the after-effects of the virus were thought to be for a short period of time (two to six weeks) but as time went on, a sub-group of survivors still had medical issues related to the virus well beyond two months.

The following is an overview demonstrating the inconsistent language that appeared in scholarly journals since the virus was identified. Labeling the long-term side effects has not been consistent. As of this writing, there are 10 labels in use. Unfortunately, an appropriate diagnostic term that describes a COVID-19 survivor who continues to experience side effects of the virus has not yet been generally accepted by the medical or other healthcare communities.

1. Long-Hauler

The term *long-hauler* (a term initially used by truck drivers when referring to long trips or ‘hauls’) identified someone who was still struggling with the after-effects of COVID-19 (Cleveland Clinic, 2020).

During the summer 2020 the international medical community continued to learn more about the virus and its residual effects as attempts were made to identify how and why the virus lingered in some patients but not others.

In addition to respiratory management, a report by Pero, et al (2020) noted that “it is critical to continue monitoring the long-term trajectory and neurocognitive outcomes of COVID-19 patients. Although extra attention to less imminent symptoms can be seen as tedious and costly…anxiety, depression, and posttraumatic stress disorder symptoms associated with COVID-19 pandemic may increase the risks of COVID-19 infected patients as well as the general population of developing neuropsychiatric disorders, which cause a predisposition to neurodegenerative processes.”

This observation is important to audiologists because cognitive issues can mimic hearing loss (focusing, paying attention, asking *“What?”* when spoken to and memory issues). Therefore, new patients might complain of hearing loss; however, the audiometric test results might not show any

peripheral hearing loss on subjective and objective tests. The patient should then be scheduled for an auditory processing evaluation.

To support this recommendation, data from a study published in the summer of 2020 from the Indiana University School of Medicine identified 50 ‘long-hauler’ symptoms (Lambert, 2020). In the top 10 were fatigue # 1 (n=1,567), difficulty concentrating/focusing #4 (n=924), memory problems #9 (n=714, ‘clogged ears’ was #35 (n=267) and tinnitus was #45 (n=233). Hearing loss (documented by audiometry) was not listed.

2. Long COVID/Long Covid

The term *long COVID* moved from social media pages online to print media in late June 2020 when a newspaper article identified that a *long COVID* support group was online (Keay, 2020).

Because *long-hauler* is not a recognized diagnostic term, a new descriptor, *long Covid*, was proposed and reported in September 2020 by Perego, et al (2020). The term was first used in Italy to describe diverse symptoms persisting beyond four weeks after symptom onset suggestive of COVID-19.

The term began being used internationally by the World Health Organization and began to appear more regularly in scholarly journals. The authors concluded that the simplicity and strength of *long Covid* as a term helps the fight for fair recognition on a global scale, and calls for care, equity, compassion, and collective action.

3. Post COVID Syndrome or Post COVID-19 Syndrome

During that same month of September 2020, another term emerged called *post-COVID syndrome* (also referred to *post-COVID-19 syndrome*). This term described the slow pace of recovery for COVID-19 patients.

Levison (2020) notes that SARS patients reported persistent fatigue, muscle pain, depression, and disrupted sleep. Except for depression these same symptoms were in the top 10 from the Indiana University study (Lambert, 2020). Although depression was not noted in the Indiana University study, ‘sadness’ was listed 24th on their list.

Levison further noted that “without a formally accepted definition of *post-COVID-19 syndrome*, it is difficult to assess how common it is, how long it lasts, who’s at risk for it, what causes it, what its pathophysiology is, and how to treat and prevent it (Levison, 2020).”

4. Ongoing COVID19 and Living with COVID

Many researchers and health-care professionals are cautious about attributing all the reported problems to a single diagnosis. It is unclear if all the people are suffering from the same disease.

In the light of this concern, in the United Kingdom, it was suggested (also in September 2020) that the use of the descriptors *Ongoing Covid19* and *Living with Covid19* should be used until evidence could support either one or more specific diagnostic definitions.

The lack of empirical diagnostic tests may mean that several different conditions may be falling

under a single umbrella term. Finally, "…the lack of a single diagnostic category in no way diminishes the very real and often severe continuing impact living with Covid19 has on people's lives (Maxwell, 2020)."

5. Postacute COVID-19

It was reported by delRio et al (2020) that there was no consensus definition of *postacute COVID-19*. Based on the COVID Symptom Study in which more than 4 million people in the United States, United Kingdom, and Sweden have entered their symptoms after a COVID-19 diagnosis, *postacute COVID-19* is defined as the presence of symptoms extending beyond three weeks from the initial onset of symptoms and chronic COVID-19 as extending beyond 12 weeks (Greenhalgh et al, 2020).

6. Chronic Post-COVID Syndrome

The term *chronic Post-COVID syndrome* had also been proposed for patients whose symptom last longer than 12 weeks (Halpin, 2021).

7. Chronic COVID Syndrome (CCS)

In October 2020, Baig called for a medical consensus on using the appropriate terminology used to describe COVID-19 survivors who were still not fully recovered after three weeks post-diagnosis. The label *chronic COVID syndrome (CCS)* was proposed. Baig rationalized that the CCS term would enable hospitals to act in concert to anticipate complications and clinically manage the patients affected by the 'chronicity of COVID-19.'

He strongly recommended to publishers of textbooks of medicine, scientific journals, and clinical practice handbooks to consider *chronic COVID syndrome (CCS)* as a distinct entity as a disease and prefer it over the other terms mentioned to describe the prolonged or *chronic COVID syndrome*.

8. Late Onset

Resources

Online Support Groups

- COVID-19 Recovery Awareness Group
- Long COVID Facebook Support Group
- COVID-19 Support Group (have it/had it) Facebook
- COVID-19 Long-Haulers Discussion Group
- Survivor Corps Facebook
- COVID-19 Longhauler Advocacy Project Facebook
- Young COVID Survivors Facebook
- Reddit COVID Support

Other Resources

- Center for Disease Control and Prevention's Coronavirus Information Page for patients
- Center for Disease Control and Prevention's Long-Term Effects of COVID-19 Page

Late onset is familiar term to anyone in the health-care profession. The term describes medical problems or a pharmaceutical's side effect that emerged days, weeks or even months after the initial diagnosis and/or start of treatment. It could also refer to the development of an age-related disease like Alzheimer's Disease or the development of Type II Diabetes.

9. Brain Fog

Brain fog is a non-medical term found online and in mass media publications used to describe memory problems, lack of mental clarity, poor concentration, and an inability to stay focused and often associated with COVID-19. It is also known as *chemo-brain* when referring to the side effects of certain drugs used in cancer management.

A search of the National Library of Medicine's (NLM) database for "*Brain Fog COVID-19*" identified six peer-reviewed research studies that used the term *brain fog* referring to cognitive changes because of the diagnosis (2021).

10. Chemo Brain

Chemo brain is a non-medical term that has been used in various media outlets to describe the same previously described cognitive decline because of chemotherapy medication(s) for cancer treatment and not specifically for COVID-19. When searching *chemo brain* on the NLM's database there were 1,517 studies listed but no studies were listed when "COVID-19" was added to the search term (2021).

Finally, The American Cancer Society's website has an excellent information page about *chemo brain* their website (2021).

COVID-19 and the Audiologist

DiSogra (2020) provides an overview of the auditory and vestibular complaints (including the incidence of tinnitus) being reported in the literature by COVID-19 survivors. This information can serve as a counseling guide for patients.

Summary

Since the spring 2020, at least a 10 labels have been or are still being used in the medical literature to describe the lingering effects of the COVID-19 virus and/or late onset of a constellation of medical problems stemming from contacting it.

The inconsistency has created confusion when reading evidence-based research. The author concurs with previously cited authors/studies that a consensus should be reached within the medical profession and medical editors about the use of a common term for this group of

COVID-19 survivors.

This inconsistency is similar to the inconsistency audiologists experienced in the 1970s and 1980s when the use of the auditory brainstem response (ABR) procedure became clinically routine.

For the younger generation of audiologists, it was not unusual 40 years ago to see articles about: Brainstem Auditory Evoked Response (BAER), Auditory Evoked Response (AER), Auditory Evoked Brainstem Response (AEBR), Auditory Brainstem Evoked Response (ABER), Brainstem Evoked Response (BER), Brainstem Auditory Evoked Potentials (BSAEP), Brainstem Auditory Evoked Response (BAER) or Auditory Evoked Potentials (AEP).

Our profession eventually settled on the term Auditory Brainstem Response (ABR) test.

In the interim, if a new patient presents with a history of COVID-19, be prepared to see one of the above COVID-19 descriptors in their report.

Conclusion

If COVID-19 patients can be followed more closely, a body of knowledge should emerge that will help audiologists better manage these persons when their auditory/vestibular symptoms result in a referral for testing.

Conductive and sensorineural hearing loss, tinnitus (including its non-organic origin) and vertigo can be expected but as of this writing there is no published research to suggest a predictable pattern (DiSogra, 2020).

Protocols for management will need to be developed; however, in the interim, an ototoxic drug monitoring protocol can serve as a reference (American Academy of Audiology, 2009).

The duration of these symptoms (after the diagnosis) can last from one day to eight weeks but, again, even in 2021, it is still may be too early in the life of this pandemic to state definitively if these symptoms are temporary or permanent.

Although no formal audiologic test protocols have been developed for COVID-19 survivors who present with auditory/vestibular complaints, audiologists should consider developing of new set of protocols for these patients. This consistency between facilities will then serve as a guide (subject to modification) if persons continue to contract the virus.

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