Understanding Long COVID: Implications for Vocational Rehabilitation Professionals - Introduction & Session 1 - From Epidemiology to Clinical Care

JOHN WALSH: Welcome to the recorded version of understanding Long COVID-- Implications for Vocational Rehabilitation Professionals. My name is John Walsh, and I serve as the project director for the Center for Innovative Training in Vocational Rehabilitation at the George Washington University. The five sessions that are part of this training series were recorded at a live mini-conference that occurred on January 11, 2023. We assembled an impressive group of subject matter experts to help shed light on post-COVID conditions and its implications in the workplace and the work you perform as vocational rehabilitation professionals.

We received a number of anecdotal reports from directors of state VR agencies that some of their consumers are being impacted by post-COVID conditions. We felt it was important to begin the process to share information that could provide you additional context to better assist those you serve, to mitigate the impact of these conditions, especially as it relates to those impacted in the workplace. We know that the knowledge around post-COVID conditions is evolving as additional research is being performed. So we hope that these modules will serve to provide you with foundational information to assist you in serving individuals who are being impacted by these conditions.

I want to first acknowledge that this training was developed with support from the Center for Innovative Training in Vocational Rehabilitation, or CIT-VR, funded by the US Department of Education through the Rehabilitation Services Administration. Opinions expressed herein do not necessarily reflect the position or policy of the US Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the US Department of Education.

The development of these training materials was a collaborative effort between a number of organizations, including the Centers for Disease Control and Prevention, the Job Accommodation Network, the Vocational Rehabilitation Technical Assistance Center for Quality Management, Yes LMS, and last but not least, the Center for Innovative Training in Vocational Rehabilitation. I want to extend my heartfelt gratitude to the presentation teams for all their hard work to put together these training sessions. I truly value the partnership and collaboration and the process to bring these modules to you. So thank you.

So let's talk a little bit about the logistics of this recorded version of the training. As the training was recorded over three hours-- that included a break-- we decided that we wanted to break this conference material into five modules. We also, during the conference, encouraged active participation, and we had sessions where there was formal presentation and then we allowed for a Q&A segment.

So the Q&A segment occurred directly after each session in sessions 1 and 2. And the Q&A segment for sessions 3 through 5 occurred after completion of session 5. In regards to CRC continuing education hours, we are offering 2.5 hours of CRC continuing education. In order to obtain your certificate of completion for this training, you will need to complete all five modules. You will also need to pass a quiz that contains 12 questions. Those questions come from all five sessions of the mini-conference.

Last, but certainly not least, you will also need to complete an evaluation of the content. We value feedback, and thank you for taking the time to complete the brief survey. So let's do a quick review of the five sessions. The five modules in this series are Session 1-- From Epidemiology to Clinical Care; Session 2-- Psychosocial Issues and the Provision of Vocational Rehabilitation Services. Session 3 will focus on the legal and service delivery dimensions. Session 4 will look at accommodations in the workplace. And the last session, Session 5, will look at the stigma of long COVID-- ethical implications for vocational professionals.

Our presenters for Session 1 are from the Centers for Disease Control and Prevention. And you will hear from Dr. Sharon Saydah and Dr. Jennifer Rittenhouse Cope. Our presenters for Session 2 are from the Center for Rehabilitation Counseling Research and Education at the George Washington University. And our presenters will be Dr. Kenneth Hergenrather and Ms. Barbara Dos Santos. So now you'll hear from the CDC team, addressing epidemiology to clinical care.

SHARON SAYDAH: Great. Thank you very much. And we're very excited to be here and to be a part of this webinar and this training. So Dr. Cope and I are going to take turns in this presentation. Our goal is for you to have a better understanding of long COVID, from the epidemiology to the clinical care. And I'm going to be presenting first.

So our general objectives for this are, first, to outline a framework for understanding of post-COVID conditions, or long COVID; present some estimates for the occurrence of long COVID; and then discuss strategies for the diagnosis, management of long COVID patients. So to start, it's important for us to understand that there are many terms used to refer to these conditions. Long COVID is one that is commonly used, both in the media, by patients, and in general that you'll see this term.

CDC, we use post-COVID conditions, with an S, recognizing that there's more than one condition associated with this. And the World Health Organization, or WHO, uses post-COVID condition. Post-Acute Sequelae of SARS-CoV-2, or PASC, is another common term that is used. And this is common from NIH's terminology, so the National Institutes of Health.

So post-COVID conditions include a wide range of new, returning, or ongoing health consequences after being infected with SARS-CoV-2, or the virus that causes COVID-19. This slide presents a general framework for understanding of post-COVID conditions. Here you can see there are two large groups of conditions that we're thinking of. The first is the general consequences of illness or hospitalizations. This includes post-ICU syndrome and other complications that patients might experience from illness or treatment of COVID-19.

The other side includes post-acute consequences of SARS-CoV-2 infection, or PASC. And these can include system-specific pathology, such as lung fibrosis, stroke, diabetes, kidney disease, and clinically significant symptoms that might have an unclear pathology, such as ME/CFS-like symptoms and dysautonomia. It's really important to remember that these conditions frequently overlap and that patients may experience any combination of these conditions.

So there are multiple proposed mechanisms for post-COVID conditions. This figure tries to summarize many of those together. So most people who have acute COVID-19 go on to make a full recovery. However, as we know, many people experience long COVID. Possible mechanisms could include viral persistence, systemic and tissue-specific inflammation, autoimmunity, and microvascular dysfunction.

Another challenge that we have with post-COVID conditions is that there really is no single estimate. There are many factors that can contribute to the variability in the prevalence in the estimates for long COVID or post-COVID conditions. These include where we find cases, so whether or not we're identifying cases from a community, from a hospital, or from other healthcare settings; the age of individuals-- we'll go through some of this in more detail; the timing of the assessment, whether or not it's soon after the infection and is three months, or if it's further out, so a year after SARS-CoV-2 infection. Demographic factors play a role, whether or not individuals were vaccinated, and if they've had pre-existing health conditions, which may predispose them to post-COVID conditions. And then finally, the choice of sample size, the design of the study, and the methodology used-- all of these contribute to various estimates and can be reasons why the estimates vary.

So now I'm going to talk about some of our estimates for the occurrence of post-COVID conditions. So first I wanted to talk about the percent of adults who've ever had COVID who currently report having long COVID. These are results from a CDC survey that's done jointly with the Census Bureau. And we found that 14.6% of US adults who ever had COVID currently report having long COVID.

From this survey, we know that it differs by demographics. So females are more likely to report having long COVID and compared to males, 17.3% to 19.3%. And we found it lower in non-Hispanic Asian compared to non-Hispanic Whites, non-Hispanic Blacks, and Hispanics.

So I mentioned some of these previously, but many of the factors that we see as associated with post-COVID conditions are female sex-- females are more likely to report post-COVID conditions compared to males; older age, with adolescents more likely to report compared to younger children, and similar, older adults more likely to report post-COVID conditions

compared to younger adults. Acute disease severity is another predictor for post-COVID conditions. So those who have been hospitalized or even in ICU or mechanically ventilated are more likely to report post-COVID conditions.

Having co-morbidities prior to SARS-CoV-2 infection also increases this, and along with those in lower socioeconomic status. And finally, those who are unvaccinated compared to those who are vaccinated prior to infection have an increased occurrence of post-COVID conditions.

So I mentioned before that we consider post-COVID conditions to be occurring four weeks or more after SARS-CoV-2 infection. And this figure shows results from the UK Coronavirus Infection Survey, where individuals reported symptoms on an ongoing basis from the time of infection for up to 20 weeks after infection. And from this graph, you can see the top line are those who tested positive for SARS-CoV-2 or COVID-19. And then the green line in the bottom are the control patients. And we see that most patients recover after four weeks. But there is a large proportion of patients who report ongoing symptoms after 12 weeks of infection. Men and women followed the same pattern, but women were more likely to report symptoms compared to men.

We also looked at post-COVID conditions among adults who survived COVID-19. In this analysis, we found using electronic health records from March of 2020 to November of 2021, we found that patients in the 30 days to 360 days after their acute COVID-19 illness, one in five were more likely to have a health condition that might be related to their previous COVID-19 illness. And these conditions included neurological or mental health conditions, kidney failure, musculoskeletal conditions, cardiovascular conditions, and respiratory conditions, along with blood clots. So as you can see, these conditions affect almost every organ system.

We do know, as I mentioned, that post-COVID conditions are less likely to occur after vaccine breakthrough. So they're less likely to occur after people have been infected if they've been vaccinated. People who've been vaccinated prior to infection are less likely to have symptoms in the 12 weeks to six months after infection compared to the unvaccinated group. They also have a lower occurrence of new conditions after infection compared to those who are unvaccinated. And COVID-19 illness in general among people who are vaccinated tends to be less severe, which also lowers the risk for post-COVID conditions.

I want to note that most of these results really focus on the adult population, and only two studies so far have included adolescents. There's some studies that have also looked at vaccination after infection and whether or not that's improved long-COVID symptoms. The results on this is less clear. Among adults who had long COVID prior to vaccination, about 30% did report an improvement in their symptoms. But 30% also reported no changes. Most of these studies are really cross-sectional and based on self-report of symptoms. We need longer followup on these. And none of these studies included children or adolescents.

I'm now going to turn it over to Dr. Cope to talk about diagnosis and management strategies.

JENNIFER RITTENHOUSE COPE: All right. Thank you, Dr. Saydah. So, yes, as Dr. Saydah mentioned, we're going to switch gears a little bit and delve a little bit more into the clinical side of long COVID. So first, while long COVID might seem like it's a completely new entity that we're just learning about with this current pandemic, and we're really starting from scratch to learn everything, what we actually have found is that long COVID has similarities to other previously described post-infectious syndromes that are listed here on this slide. These also have symptoms of fatigue, cognitive dysfunction, sleep disturbances, and pain.

Some examples include post-intensive care syndrome, post-treatment Lyme disease, post-viral fatigue syndrome, and ME/CFS, which is the acronym for Myalgic Encephalomyelitis Chronic Fatigue Syndrome. Many cases of ME/CFS are also thought to be triggered by a viral illness. Long COVID, with its similarities to ME/CFS, might provide an opportunity to better understand both illnesses.

Patients with post-COVID conditions or long COVID often present with a complex clinical picture that makes diagnosis challenging. There's no single diagnostic test to identify patients with post-COVID conditions. In many cases, COVID-19 might not have even been documented with a positive SARS-CoV-2 test. Some reasons for this included a lack of access to testing early on in the pandemic, testing prior to or after the viral levels were detectable, or a false negative result. This should not exclude the clinical diagnosis of post-COVID conditions if someone does not have a positive test in their history.

Patients can report numerous symptoms. The number and temporal fluctuation and intensity of the symptoms recorded might not fit recognizable clinical paradigms. And clinicians sometimes have difficulty accepting a patient report of symptoms. This can be particularly problematic when routine tests are normal. And so as a result, patients can feel misunderstood and stigmatized by their healthcare providers.

In addition, at this point in time there's no clinical trial or evidence-based management outcomes available to guide clinicians specifically in how to treat long COVID. So here, this site has a list of symptoms from CDC's website on post-COVID conditions, illustrating the wide range of symptoms involving multiple body systems. And this list is not exhaustive. Some of the most commonly reported symptoms include fatigue, post-exertional malaise-- this means symptoms that get worse after physical or mental effort-- and shortness of breath or dyspnea. Other commonly reported symptoms include cognitive impairment or brain fog, sleep disturbances, and chest pain.

CDC has information for healthcare providers on evaluating and caring for patients with post-COVID conditions. A few highlights from this content includes most post-COVID conditions can be diagnosed and managed by primary care providers. While there are specialized clinics that have been established for treating post-COVID conditions, these are often located in urban areas at big academic medical centers and might have long wait lists to be seen and might not be readily accessible to some patients. Many patients might not have access to this type of specialized care, so there is a need to empower primary care providers to take care of long COVID patients.

Many post-COVID conditions may be diagnosed based on history and physical exam alone, and often routine testing might be normal. Because this testing might be normal, consider a conservative diagnostic approach in the first four to 12 weeks. That being said, if a patient does have concerning signs or symptoms or life-threatening symptoms, an urgent workup should be done to rule out any life-threatening conditions. Symptoms persisting beyond three months might prompt a further evaluation. Listen to and validate patients' experiences and partner with patients to identify achievable health goals.

We also want to note, if you're not already aware, that as of October 2021, there is a specific ICD-10 code for post-COVID conditions. That is U09.9. This is important and will enable us to better use healthcare administration data to track post-COVID conditions. CDC also has some resources available for patients and healthcare providers to use as they determine how to navigate a healthcare appointment for long COVID.

First, for healthcare providers, listen to the patient's story. Some of these patients might have been to other healthcare providers already who haven't taken their symptoms seriously or told them that it was all related to stress or anxiety. So healthcare providers can go a long way to help a patient by simply listening to them and taking them seriously.

Some questions to consider asking during a healthcare visit for long COVID might be what is your activity level? What activities make your illness worse? And what improves or worsens your symptoms? It can also be helpful to outline the next steps, including what additional tests are needed, when those test results will be available, and when they should return for the next visit.

Here's an example of a resource available on CDC's website for use by patients to prepare for a long COVID healthcare appointment. This checklist outlines steps to take before the appointment, during the appointment, and afterwards. One of the medical professional organizations that has been very active in addressing long COVID is the American Academy of Physical Medicine and Rehabilitation, or AAPM&R.

In March 2021, they launched a multidisciplinary task collaborative of experts. Since the establishment of this collaborative, they have released six clinical guidance statements addressing assessment and treatment of fatigue, breathing discomfort, cognitive symptoms, cardiovascular complications, and most recently, autonomic dysfunction, and guidance aimed at the pediatric population. Links to these clinical guidance statements can be found at AAPM&R's website.

Switching gears a little bit, the next two slides will highlight-- come from our colleagues at the Department of Health and Human Services, or HHS, and highlight some of the work other federal agencies are doing to address post-COVID conditions. On April 5, 2022, President Biden issued a memorandum which charged the Secretary of Health and Human Services with coordinating a government-wide response to long COVID and the longer term effects of COVID-19.

This slide talks about the services report, which is broad and its intent and outlines federally funded, mostly pre-existing programs for individuals experiencing long-COVID and those impacted by the longer term effects of the pandemic. It's a consumer-facing tool that catalogs more than 200 federally supported services, which also include resources for healthcare personnel caring for individuals with long COVID. We encourage you to share these resources with your patients. They are available at www.covid.gov/longcovid. The Office of the Assistant Secretary for Health, or OASH, has been working to make the report more navigable by adding resources and building out their new long COVID website.

The second report that was released was the National Research Action Plan on Long-COVID, which proposes a comprehensive research strategy with a focus on equity to inform the national response to long COVID. The plan is intended for US government agencies and to inform Congress and researchers, both public and private, including academia. It's also relevant to multiple other groups, including the general public.

The plan outlines over 72 active research programs in place. And new research and publications are emerging regularly, which often have implications for clinical practice. The largest two studies highlighted in this National Research Action Plan include CDC's Innovative Support for Patients with SARS-CoV-2 Infections, or the INSPIRE study, and then the NIH Recovery Initiative, which has multiple cohorts in separate studies, which includes studies using electronic health record data of over 60 million adult and pediatric records and has over 40 studies of the underlying biology responsible for long-COVID.

And just to note, there's currently a continued need to enroll people in the NIH recover studies, particularly people who've had a recent positive test result. And there's information here to refer those patients to the NIH portal to enroll in a study in their community. And that NIH portal can be found at recoverCOVID.org.

So a couple of take home messages-- While we're still learning, a lot to learn yet on post-COVID conditions, we do have a couple of important messages. First is the importance of the S on post-COVID conditions. So post-COVID clinical outcomes are complex and are not one single entity. And this can make simple case definitions hard to generate or impractical and presents challenges for standard disease surveillance methods. In addition, the clinical complexity precludes detailed and specific clinical guidance. Studies characterizing the different phenotypes, risk factors, and biomarkers are needed, and these are ongoing.

Second, estimates on the occurrence of post-COVID conditions range widely, depending on the methodology used. But what we can say is that they are likely not uncommon following an infection of the SARS-CoV-2 virus. And finally, it is clear that the patient advocacy community does have some concerns about how the government and healthcare systems are meeting their needs. And so continuing to work on improved collaboration is necessary to provide better integration of the range of services that are needed for this patient group.

Thank you for your time. And with that, we can move to Q&A.

MODERATOR: OK, we do have a few questions in the Q&A. So the first is from Karen, and she wondered, could you please give an example of post-ICU hospitalization treatment, which was indicated on the slide? I think it was one of the earlier slides.

JENNIFER RITTENHOUSE COPE: I can start. I think Sharon and I both mentioned that in our slides. So post-ICU syndrome, or PICS is actually an entity in and of itself, and it's not specific to COVID-19. It actually can be seen after any serious illness that requires care in an intensive care unit. So it's a consequence of all the different kinds of treatment and management that occurs in an ICU, including things like just generalized weakness following an illness that requires an ICU stay. So I think the main thing I want to point out is it's not specific to COVID-19. But certainly there were people that required ICU care for their COVID-19 illness, so it can occur from that.

MODERATOR: OK. There's another question from Sharon Wilcox. She said, is there any research showing why females have a higher reported long COVID diagnosis as opposed to males?

SHARON SAYDAH: I can start, and then I'll let you pick it up. So in terms-- a couple of things to remember. So in terms of report of new onset conditions, so we mentioned that people who've had COVID-19 seem to be at an increased risk for stroke, and diabetes, and cardiovascular disease, and kidney disease, many of these ongoing conditions. We don't see as much of an increased risk among females compared to males. However, which is probably even more important for folks, the ongoing symptoms, which can be very debilitating and impact work and other activities, we do see an increased risk for females compared to males. And Jen, I don't know if you want to comment further on that from other work that you've done.

JENNIFER RITTENHOUSE COPE: Sure. Yeah. I think where we do see more of that discrepancy is in these symptoms of fatigue, post-exertional malaise, cognitive dysfunction, that entity that we don't have a good explanation for but we're seeing a lot of following SARS-CoV-2 infection. I think that's where we see a little bit more of the female predominance. And so that is something that is also seen in ME/CFS and other post-infectious fatiguing illnesses.

So I don't think we have-- we don't have a concrete explanation for that. But I think some of the theories go along with, actually Sharon's slide, where she talked about the proposed hypotheses for long-COVID. Autoimmunity is one, and autoimmune diseases are also more commonly seen in women. So those are a couple of the thoughts, a couple other things. And Sharon might be able to comment on this is just that healthcare-seeking behavior. Women are more likely to seek healthcare. So those are a couple of thoughts on that. But the bottom line is we don't necessarily know the exact reason why.

MODERATOR: Thank you. Amy had talked about being in the emergency room, and the doctor had talked about that the new strain was really particularly virulent and that the current boosters may not help with symptoms or catching COVID. So do you have any information about that?

SHARON SAYDAH: We do know that the new vaccines do work in reducing the severity of COVID-19. And just in terms of symptoms, we have looked some in terms of ongoing symptoms by different variant periods, so comparing Delta to Omicron. And there are a number of symptoms that we see more common in the earlier variant periods than we see now. And there's some indication that, because people are more likely to be vaccinated when they are infected, now that we're seeing reduction in ongoing symptoms.

MODERATOR: OK. The next question, someone asked is hair loss one of the symptoms of long COVID?

JENNIFER RITTENHOUSE COPE: Yes. That has certainly been reported. I can't remember if it is on the list of-- or on the slide where I had the list of symptoms. But since that list is not exhaustive, actually hair loss has certainly been reported and would be considered a possible symptom of long-COVID.

MODERATOR: This attendee asked, is the research for symptomatic infection, or were asymptomatic infections also included in the long-COVID studies?

SHARON SAYDAH: That really depends on the studies. Like I mentioned, the methodology varies greatly across the studies. There have been some that have included asymptomatic infection. And some, especially those that are based more on electronic health records, would have infections that presented to a healthcare setting, so also more likely to be the more severe infections and not necessarily people just testing at home.

MODERATOR: OK. The next question asks, does long-COVID look different between groups who have been vaccinated and those who have not been vaccinated?

SHARON SAYDAH: So I think the question is trying to get at whether or not the symptoms and conditions that we're seeing comparing the vaccinated and unvaccinated groups are different. We do know that people who are vaccinated prior to infection are less likely to report ongoing symptoms or new conditions. And it reduces that occurrence by up to 50%.

MODERATOR: Regina asks, when you talk about people being vaccinated doing better post-COVID, does it matter how long ago the vaccination is?

SHARON SAYDAH: Yeah. So there have only been a few studies that have looked at that, where people were infected, had long COVID, and then got vaccinated. And honestly, I'd have to go back and look, but I'm not sure if they took into account how long the time since vaccination was.

MODERATOR: Thank you. Next question was from Gloria Meadows. And the question was, are over-the-counter kits such as Binax effective for COVID screening and also including post-COVID? I think what Gloria is asking is about long COVID screening.

JENNIFER RITTENHOUSE COPE: I can start with that. So there's no-- so most people with long COVID, while viral persistence is potentially a mechanism that causes long COVID, most people with long COVID-- most people, after several weeks, have cleared the virus. So if you're doing the test that's available over the counter with the nasal swab, you're not going to get a positive result. Or even if you did a PCR, you're probably not going to detect it that way either.

So the viral persistence might be in more parts of the body, other parts of the body that aren't routinely being tested. And that again is just still hypothesis. We haven't seen a lot of evidence for viral persistence. And then as far as whether you're-- if you have a patient who has fatigue and headaches, has a constellation of symptoms that could be related to-- could be long COVID, there is not a single diagnostic test to be able to say that. So that's why the diagnosis is going to be made based on their history, have they had COVID, whether that was with a positive test or just by the constellation symptoms they had, a physical exam, possibly some testing, although I did mention that a lot of routine blood work is likely going to be normal. And that's what makes this a challenging diagnosis because, as physicians, we like to have a single test that gives you an answer, and that's not the case here.

MODERATOR: Kieran asks, were any of the studies on long-COVID focused on people with disabilities to collect data on their treatment and access to healthcare for long COVID treatment?

SHARON SAYDAH: Did you want to--

JENNIFER RITTENHOUSE COPE: Oh, I'm just smiling because I just have a paper coming.

SHARON SAYDAH: Oh, yeah. So we do have a paper soon coming out that's looking at the report among people with disabilities, what their report of ongoing symptoms and long COVID is. And so we have started to look at that. That is definitely of interest because we know that people with disabilities are also at an increased risk for COVID-19. And so that will put them also at an increased risk for post-COVID conditions.

MODERATOR: And if I could just follow up on that-- and where will that paper be coming out? It will be in one of the medical journals?

SHARON SAYDAH: It should be published in the next two weeks, I think, in Disability -- Disability Research. Is that right? I think that's right.

JENNIFER RITTENHOUSE COPE: Double check. I know "Disability" is in the journal name. Yes.

MODERATOR: OK. The next question comes from Susan Foley. She said, does the CDC consider long COVID to be a disability?

JENNIFER RITTENHOUSE COPE: So the answer is yes. And the entity that has designated it as-- or that it can be a disability, I believe-- we used to have a slide on that. And so, yes. Yes, it can be a condition that leads to disability. Yes.

MODERATOR: And Ned asks, are there any cases of individuals that recovered from COVID and they're infected a second time resulting in long COVID?

SHARON SAYDAH: So each time you're infected with SARS-CoV-2 and you have COVID-19, you're at a risk for having post-COVID conditions. There has been one study that looked at people who were infected multiple times and their risk of long COVID. They did find that there was an increased risk among these people. But I just want to note that that population also was more likely to have severe disease and had a number of underlying conditions, also putting them at increased risk for long COVID.

MODERATOR: Mallory Watts asked, is there a study or group for my client who did the vaccines and had COVID and now has long COVID reactions? Would it be benefit for this client to participate or inquire with recoverCOVID?

JENNIFER RITTENHOUSE COPE: Absolutely. I think so, yes.

MODERATOR: And could you give us that website again?

JENNIFER RITTENHOUSE COPE: RecoverCOVID.org. RecoverCOVID-- all one word-- dot org.

MODERATOR: Thank you. I know we only have about one minute left, but Christine asked, are there any studies or information that looks at a patient's vitamin D level and long COVID?

JENNIFER RITTENHOUSE COPE: There could be. I don't know for sure. [LAUGHS] Yeah. We're not familiar with any, but that's not to say that there aren't.