WHAT YOU NEED TO KNOW ABOUT COVID IN 2024: **A CONVERSATION FOR DV** AGENCIES, SOCIAL JUSTICE PROFESSIONALS, ADVOCATES, AND PREVENTIONISTS

Olivia Belknap and Erin Batali MFT associates



atention

- A lot of the information presented today may be new for you, and some of it might be upsetting or stressful
- You may experience feelings of anger, fear, anxiety, sadness, defensiveness
- Notice what's coming up for you and acknowledge it without judgement
- Notice how your nervous system is responding, and do what you need to do to regulate so you can stay engaged
- The goal is not to **do anything differently right now** just to stay open and listen

Curiosity

- What feelings come up when you consider the possibility that the COVID pandemic never ended?
- The possibility that COVID is worse than many of us thought? The possibility that the impacts of COVID are not going away?
- If you used to wear a mask in public and no longer do, why? What do you know about how the COVID virus has changed over time?
- What may be preventing you from considering you might be wrong (or at least missing something) in calculating the risk/negative effects of COVID?

WHAT'S IN THIS PRESENTATION



WHAT IS COVID?

03 **IMPACT ON THE BODY**



IMPACT ON THE BRAIN





RELATIONSHIP IMPLICATIONS



ADVOCACY & RESOURCES





The pandemic is over	The public en
"It's just a cold now"/"It's mild"	Leads to signifi
Spread through droplets	Airborne, car
Masks don't work	N95s are bes [.]
Vaccines are all we need to be protected from infection, Or "Vaccines don't work"	Vaccines reduces and infection.
Only X people are impacted	Anyone can g
You can only get COVID once	There is no limit COVID; damage
Only spreads indoors	Outdoor spre
Only need to isolate for 1-5 days	Continue isol testing positi
"I don't have symptoms so I don't have COVID"	Up to 50% of (asymptomati

NOW WE KNOW...

nergency has ended

- cant long term health problems
- hang in the air for hours
- t protection
- ce rates of death, hospitalization, Important to get boosters. Best e other safety measures.
- get long COVID
- to the number of times you can get is cumulative; no lasting immunity
- ead
- lating if symptomatic or
- ve
- COVID spread is from
- c or presymptomatic infections

COVID & THE BRAIN

- Neuro-invasive
- Memory loss
- Paresthesia
- Dizziness and balance issues
- Sensitivity to light and noise
- Loss of (or phantom) smell or taste
- Autonomic dysfunction
- Depression and anxiety
- Insomnia
- Increased suicide risk
- Increased risks of cognitive impairment (brain fog), seizures, dementia, psychosis, and other neuro-cognitive conditions continued for at least 2 years
- Overall reduction in brain size
- 0

Similar rates in hospitalized and nonhospitalized patients

- Neurological symptoms often have a
 - **delayed onset** of weeks to months, and can **worsen over time**
- Lack of concentration, difficulty in
 - understanding instruction, and difficulty in processing information, short-term memory problems
- may appear similar to ADHD
 A subset of those with cognitive impairment may not know and/or report their impairment

LONG COVID

"Experiencing symptoms within three months from the initial infection that last at least two months" Pollock et al 2023

- Affects 20-30% of all patients (50% of hospitalized patients)
- Most long COVID cases are in non-hospitalized patients with a mild acute illness
- Over 200+ potential symptoms American Medical Association
- LC pathophysiology includes: immune dysregulation and autoimmunity, pathogen persistence/reactivation, neurological abnormalities and neuroinflammation, tissue and organ damage, hypoperfusion and autonomic dysfunction, fibrin amyloid microclots, and microbiome dysregulation

"We should not be thinking about long COVID as something that happens to certain groups of people. It can affect anyone of all ages." Weiss (2023)



GASTROINTESTINAL





LUNGS





LONG COVID

- Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
 - Neuroimmune illness characterized by intolerance to systemic exertion and chronic fatigue that cannot be alleviated via rest
 - 58.7% met the criteria for ME/CFS
- **Respiratory**: cough, breathing difficulty
- Gastrointestinal: heartburn, gastrointestinal disorders, constipation, loss of appetite, and abdominal pain
- COVID-19 is capable of inducing <u>multiple systemic and organic</u> lesions
 - 70% of individuals with long COVID exhibited evidence of damage to at least one organ
 - Multiorgan damage: renal, thrombotic, cardiac, and pulmonary functions
- **Pancreas**: pancreatitis, diabetes, pancreatic exocrine dysfunction
- **Musculoskeletal:** musculoskeletal pain, sarcopenia and decreased skeletal muscle mass

Davis et al., 2021; Demoliou et al., 2022; Donders et al., 2022; Dorobisz et al., 2023; Li et al., 2023; Polly & Fernandez, 2022; Ripa et al., 2022; Seyfi et al., 2022

Other symptoms

- Hair loss
- Tooth loss
 - Skin problems blisters, rash, "COVID toes"
- Immune dysregulation Lymphopenia
- New cancers
- Vision & hearing loss
- Blood clots
 - heart attack, stroke, pulmonary embolisms
- Inflammation
- Anaphylaxis and new allergies
- Changes in sensitivity to medication
- Seizures
- Facial paralysis
- Sleep issues
- Autoimmune disorders

POTENTIAL CAUSES OF LONG COVID

- Inflammation, neuroinflammation & autoimmunity
- Reduced serotonin
 - Vagus nerve dysfunction
- Autonomic dysfunction
- Virus crossing blood-brain barrier
- Viral persistance
- Organ and tissue damage
- Microclots





Source: GAO analysis of medical literature. | GAO-22-105666



LONG COVID Who is high risk? According to the CDC



- "People from racial and ethnic minority groups"
- Pregnant people
- Infants
- Adults 65+
- Disabilities: Autism, ADHD, learning disorders, Down syndrome, & more
- Cancer
- Asthma
- Immunocompromised
- Connective tissue disorders (hEDS)

- Mental health conditions: mood disorders
- Current/former smoker
- Substance use disorders
- Stroke
- Heart Conditions
- HIV
- Diabetes
- Autoimmune diseases
- Chronic kidney/liver/lung disease
- Mast Cell Activation Syndrome (MCAS)
- and MORE

• 75.4% of U.S. adults had at least one increased-risk condition

40.3% ≥2 conditions

 18.5% ≥3 conditions (data from 2021) Ajufo et al. 2021

Psychiatric disorders are associated with increased risk for being hospitalized and/or having subsequent health complications from COVID Schultebraucks et al. 2023

LONG COVID

- Risk increases with each subsequent COVID infection Bowe et al., 2022
- There are no proven effective treatments for LC, partly due to no identifiable cause Highleyman, 2023
- LC is associated with preexisting psychiatric disorders, post-infection psychiatric disoders, and suicide risk
 Gasnier et al. 2023
- Symptoms can last weeks, months or years. Some conditions will be lifelong. Symptoms may remit and then return.



Between 10-30% of those who have had COVID will develop Long COVID

(Some studies show higher rates)





How is your body reacting to this information? What do you need to regulate your nervous system?

SOCIAL JUSTICE CONSIDERATIONS

- Disproportionately impacts BIPOC folks, women, LGBTQ+, low income & disabled people
- Accessing medical care
 - Ending the state of emergency removed social supports
 - Private companies increasing cost of treatments
 - Private resources shutting down
 - Patient gaslighting from the medical system
- Ableism: "set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or psychiatric disabilities and often rests on the assumption that disabled people need to be 'fixed' in one form or the other" _{Smith (2023)}

"The more people perceived there to be racial disparities, the less fearful they were of COVID-19, and the less they supported safety precautions to prevent the spread" (NPR)

SOCIAL JUSTICE CONSIDERATIONS

about getting a serious case of COVID-19

% of U.S. adults who say they are ____ concerned that they ...

Will get COVID-19 and require hospitalization

White people are less concerned about getting COVID and spreading it to others



Those with lower incomes express more concern





28

41





SOCIAL JUSTICE CONSIDERATIONS

Figure 21

About Four In Ten Say They Have Taken Recent Precautions Because Of Increases Of COVID-19

Percent who say the news of increases of COVID-19 made them...

White people are
significantly less likely
to take COVID
precautions





NOTE: Persons of Hispanic origin may be of any race but are categorized as Hispanic for this analysis; other groups are non-Hispanic. See topline for full question wording.

SOURCE: KFF COVID-19 Vaccine Monitor (Sept. 6-13, 2023)



SOCIAL JUSTICE COVID is a workers rights issue

- "Public facing industries, including teaching and education, social care, healthcare, civil service, retail and transport industries and occupations, had the highest likelihood of long-COVID" Kromydas et al., 2023
 - 11.6% (teaching and education)
 - Prevalence of reduced function by 'a lot'
 - 22%–23% (teaching and education)
- "Around 16 million working-age Americans (those aged 18 to 65) have long Covid today"
 - $\circ\,$ 2 -4 million are out of work due to long Covid
 - Consider the impact of worker shortages on various industries: teaching, healthcare, pilots,

etc

 Paid sick leave Childcare Healthcare Protective equipment Disability accomodations Who is liable for infection?

SOCIAL JUSTICE & COMMUNITY CARE

"When I am in public spaces and see most people unmasked either because they think the virus is a hoax, that masking is virtue signaling and a sign of weakness, aren't thinking about it, or that they simply don't care, I feel like <u>an expendable burden not</u> worth saving" - Alice Wong

"The psychological toll of trying to keep ourselves safe with no institutional support, and, in fact, quite a bit of institutional propaganda that we are being hysterical, is an ongoing source of trauma. It feels like I'm screaming into the void." - Angela Meriquez Vázquez Wong 2024



"Being chronically ill right now means navigating systems with constant reminders of how little the people in those systems value you. We emotionally support each other when the world seems to want to forget that we exist." -Kimberly Vered Shashoua, LCSW COVID-conscious therapist



LGBTQ+ ISSUES:

Demographics of long COVID in the US:

- 13.5% cisgender men
- 21.8% cisgender women
- <u>26.3% of trans adults</u>
- 16.8% of straight adults
- 18.7 of gay and lesbian adults
- 28.4% of bisexual adults CDC 2024

"<u>Allowing COVID to proliferate is</u> <u>going to continue to worsen health</u> <u>disparities</u>... particularly in a country where in some places, it's literally illegal to give appropriate health care to trans people." JD Davids



"Of course [trans people] have higher rates of long COVID. We have lower rates of being treated as humans. <u>People</u> who are denied access to health care, resources, or bodily safety are at higher risk of ill health outcomes, including this massive disabling event known as long COVID." JD Davids



Long COVID Kids



Signs of Long Covid often look different in kids vs adults

tired after school or activities

behavioral issues

drop in grades or school performance

food avoidance

uninterested in play or activities

sensory issues

	Neurological		
	Symptoms • Headache • Paresthesia • Dizziness • Vertigo • Tremulousness		
	Conditions • POTS • Orthostatic intolerance • Dysautonomia • Pediatric acute- onset psychiatric syndrome		
	Respiratory Symptoms • Shortness of breath • Chest pain • Chest tightness • Cough • Exercise intolerance		
GI Symptoms • Nausea • Vomiting • Abdominal pain • Diarrhea/constipation • Weight loss • Loss of appetite			
	Reproductive Symptoms • Irregular periods		

Musculoskeletal		
Symptoms	Conditions	
 Weakness 	 Myositis 	
 Myalgia 	-	
 Arthralgia 		

Mental Health/Behavioral

Symptoms

- Decreased school performance • Brain fog/cognitive difficulties
- Low mood
- Difficulty with concentration Memory problems
- Suicidal behavior
- Irritability
- Impulsivity
- Somatization
- Emotional lability

Conditions

- Anxiety
- Depression
- Posttraumatic stress disorder
- Stress and adjustment disorders
- Attention-deficit/hyperactivity disorder
- Eating disorders

Rao et al., 2024

Conditions

ME/CFS

Constitutional

Symptoms

- Fatigue
- Sleep disturbance
- Fever
- Malaise
- Weakness
- Generalized pain
- Post exertional malaise
- Somnolence

Otolaryngology

- Nasal congestion

Conditions

- Abnormal smell or taste
- · Loss of smell or taste
- Paradoxical vocal cord motion dysfunction

Cardiovascular

Symptoms

- Palpitations
- Tachycardia
- Syncope
- Dizziness
- Chest Pain
- Exercise intolerance

Conditions

- POTS
- Myocarditis
- Arrhythmias
- Conduction abnormalities
- Hematological
- Hypercoagulability

- Mast cell activation
- syndrome

Dermatologic

- Aphthous ulcers
- Symptoms Conditions Hair loss
 COVID digits
- Rashes

- Symptoms
- Chronic rhinorrhea

Conditions

Leucopenia

- Thrombocytopenia

Thromboembolism

Mastocytosis



How is your body reacting to this information? What do you need to regulate your nervous system?

Couples & Relationships

- Varying levels of precaution: "34% of US adults reported conflict with their partners related to their COVID-19 health concerns or the continuing [prevention measures]"
 - "Three year relationship that I thought would be life long ended over different levels of precaution" -@BeGillz
 - "It doesn't help when your in-laws don't believe in precautions either and causes tension indirectly" -@KayleighsCreat1
 - "They started engaging in high risk behavior and lied to me about them"-@TitheGirl
 - "It is absolutely an issue for couples. And parents. And children with siblings who aren't approaching the pandemic in a similar fashion, etc. When you share AIR and everything that comes with it, individual actions have collective consequences. It's TOUGH" -@kadamssl (Therapist)



Couples & Relationships

- Intimate Partner Violence: "Partners weaponized [the patient's] long Covid symptoms to further perpetrate abusive and controlling behaviours."
 - "too unwell to even consider leaving their abusive partner"
 - "my bf isn't masking anywhere or taking any precautions even though I'm immunocompromised. I can't afford to leave so I just kinda have to pretend to **be okay with it**" -@freglysleftfoot
- Changing relationship/family dynamics due to health issues
 - What happens when one member of the couple is no longer able to perform the care duties they used to?
 - Personality changes or increased anger/aggression
 - Lost income due to health issues
 - Loss of sexual functioning
 - Partners becoming a caregiver unexpectedly



COVID PROTECTION

How to make spaces safer and more accessible to all







ADVOCACY, HARM REDUCTION & COMMUNITY CARE

lhat can



EARG MASK

Mask blochttps://maskbloc.org/ KN95 or better for optimal protection



Advocate within your community spaces

INFORMATION

- What to do if you have COVID
- <u>Risk status questionnaire</u>
- What is Long COVID
- <u>Up-to-date research articles</u>
- Long COVID Families support
- <u>People's CDC: Evidence-</u> based updates
- <u>CDC wastewater data</u>
- <u>COVID Safety 101</u>



COVID PREVENTION & CARE • <u>Quality masks (1)</u> <u>Quality masks (2)</u>

- Mask Bloc Finder

COMMUNITY CARE

• Long COVID support groups

• <u>COVID advocacy groups directory</u>

<u>COVID-conscious therapists list</u>

<u>Covid Isn't Over/Still Coviding</u>

<u>"Why should I care?" FAQ</u>

<u>Community Events (LGBTQ+, BIPOC)</u>

liscussion

What feelings came up for you?

What's something new you've learned today?

How will you implement what you've learned today in your own lifeeither personally or in your professional practice?

Do you have any questions?



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