Long COVID Patients: They are changing how clinicians think

Q&A

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Dr. Julie Barroso is the Julia Eleanor

Blair Chenault Endowed Professor at the Vanderbilt University School of Nursing. Prior to this, she was the Assoc. Dean of the Faculty at the Medical University of South Carolina College of Nursing. Her current research involves the development of a cognitive-behavioral stress management app to ameliorate HIVrelated fatigue, and a stigma reduction intervention for women living with HIV. Dr. Barroso is also a qualitative methodologist and developed with Dr. Margarete Sandelowski the technique for qualitative metasynthesis. She has served on national and international boards related to HIV infection, as well as serving on local boards in communities in which she has lived. She has recently become interested in Long COVID and submitted a grant in February to determine symptom clusters in Long COVID and their impact on functioning.



Bishop Oliver Clyde Allen III is a religious trailblazer, author, human rights advocate, an international and community leader, and an entrepreneur. He is the senior pastor and founder of The Vision Cathedral of Atlanta, known as "The Vision Church," and the founder and the Presiding Bishop of the United Progressive Pentecostal Fellowship of Churches (UPPC). Allen was appointed by President Barack Obama in 2015 to the Presidential Advisory Council on HIV/AIDS. Bishop Allen has served as

the Southeastern chair of the Democratic National Committee LGBT advisory board, co-chair of the DNC

LGBTQ policy group, and Atlanta Mayor Keisha Lance Bottoms' LGBT advisory board. He also has served as national ambassador and consultant for the NAACP's The Black Church and

HIV initiative. He is currently a Commissioner on the Atlanta Human Relations Commission and executive director of Vision Community Foundation Inc.



Dr. Sarath Raju is an instructor of medicine at the Johns Hopkins University School of Medicine. His areas of clinical expertise include obstructive lung diseases, chronic lung disease in persons living with HIV, and critical care medicine. Dr. Raju earned his M.D. from Rush Medical College. He completed his residency at Johns Hopkins, where he also performed a fellowship in pulmonary and critical care medicine. He previously served as an Assistant Chief of Service for the Osler Medical Housestaff Training Program at Johns Hopkins. Dr. Raju joined the Johns Hopkins faculty in 2020 and is supported by the NIH to conduct research investigating the intersection of HIV, environmental exposures, and lung health.



Faculty

Question and answer

Considering delirium in patients with Long COVID: Is anyone looking at potential oversedation, such as overuse of second-generation antipsychotics (e.g., quetiapine)?

Julie Barroso, PhD, RN, ANP, FNAP, FAAN: I do not know if anyone is examining this at all. I think most health care providers are still trying the steps I listed on my slide which are preventative measures.

These steps include:

- Delirium prevention and treatment assess each shift; cognitive activities; sleep/wake cycle; hearing aids/eyeglasses; mobility; hydration; pain management.
- Social isolation increases risk of delirium; video conferencing, engaging the individual be reassuring, smile behind the mask.
- Early progressive mobility helps with delirium and deconditioning.

How can healthcare professionals become involved in Long COVID research?

JB: If you have the appropriate training, you can look at the many calls for proposals that are already out there, e.g., NIH. If not, and you want to be an assistant on a grant, I would check with the Infectious Diseases Clinic if you are in an academic health center, or if you have a Long COVID clinic near you, contact them and ask if you can be involved in any way.

Is the study at John Hopkins University in-person or virtual?

Sarath Raju, M.D., M.P.H.: The study started off as virtual, but we are now <u>seeing</u> patients both inpatient and virtual.

Who can you contact to refer a patient to a study?

SR: Email <u>pact@jhmi.edu</u> to hear more about services available through the Johns Hopkins Post-Acute COVID Team (PACT).

How representative is the data of asymptomatic people or those whose symptoms were mild enough that they were not hospitalized?

JB: In the patient-sourced studies I discussed, most of those participants were not hospitalized, but if one goes on to develop Long COVID, the symptoms of the tested/never tested/hospitalized/not hospitalized were remarkably similar once they advanced to Long COVID. As I mentioned, the only difference in the studies I examined was that those who had never been tested reported low rates of loss of smell/taste. I do not know of any patient-sourced studies that examine asymptomatic people because by definition, those folks do not have Long COVID.



SR: The current data regarding the non-hospitalized patients in our studies are not representative. As we are often selectively seeing patients with ongoing issues who choose to seek care. Ongoing surveillance efforts are trying to gather more data on post-COVID effects in both hospitalized and non-hospitalized individuals to get a better sense of the true prevalence of post-acute COVID-19 / Long COVID.

Is there any research on post COVID-19 effect on fertility?

SR: Research is ongoing in this area. Read the <u>Impact of COVID-19 on female fertility: a</u> <u>systematic review and meta-analysis protocol</u>

What lessons have both researchers and clinicians learned from Long COVID?

JB: For me, the real take home message is that we must listen to what patients tell us, and even if we do not understand something, we cannot say that it does not exist. Also, we cannot recommend interventions until we are clearer on what is causing Long COVID.

SR: One major lesson has been gaining comfort admitting what we do not know. We are still early into our understanding of Long COVID, and I think it is important to admit what we do not know, and realize we still have a lot more to learn. Additionally, we have further learned the importance of multidisciplinary teams in both COVID-19 research and clinical care. Our care for Long COVID patients requires a multidisciplinary team including nurses, home care specialists, physical therapist, and physicians across different specialties to allow us to better understand and address the needs of these patients.

What type of interventions can be provided to support patients with psychological trauma post COVID-19?

SR: We are still working on targeted strategies to address this as we learn more about long-COVID. Currently we are applying strategies that have been successful in general population with post-hospital / post-ICU syndrome. This involves targeted strategies for rehab from physical therapists and physiatrists in addition to multidisciplinary care from psychiatrists, rehab psychologists, and neuropsychologists. Post-COVID clinics are being developed across the country that integrate these services to aid COVID-19 survivors.

In Nigeria, recovered patient still face stigmatization. What do we do to decrease the stigma surrounding COVID-19?

JB: This is a tough one. It will take a lot of understanding on the part of the public; they must be educated about what Long COVID is. Stigma with any disease is very tough to tackle because it requires us to get people to let go of their beliefs...we see how tough that is even with the COVID vaccine! Eventually, we may need to educate patients with COVID to feel empowered enough to blunt the impact of stigma.





Please visit the <u>COVID-19 Prevention Network</u> (CoVPN) website for educational programming about vaccine and therapeutic trials, community education and engagement. For daily updates, follow CoVPN on <u>Facebook</u>. You can also view informational videos on the <u>CoVPN YouTube page</u>.

For other COVID-19 resources, visit our website and refer to <u>previous updates and recorded</u> <u>webinars</u> for additional information.

Additional Long COVID-19 Resources

When COVID-19 Symptoms Linge: New NIH initiative seeks to understand why some people continue to have symptoms long after recovery

Cleveland Clinic Journal of Medicine: **Post-acute sequelae of SARS-CoV-2 infection: Caring for** the 'long-haulers'

Johns Hopkins COVID Long Study

Patient-Led Long COVID Research Collaborative

