

**GLOBAL FEMINISMS
COMPARATIVE CASE STUDIES OF
WOMEN'S AND GENDER ACTIVISM
AND SCHOLARSHIP**

SITE: UNITED STATES

**Transcript of Lisa McCorkell
Interviewer: Abigail Dumes**

**Location: Virtual
Date: June 30, 2022**

**University of Michigan
Institute for Research on Women and Gender
1136 Lane Hall Ann Arbor, MI 48109-1290
Tel: (734) 764-9537**

**E-mail: um.gfp@umich.edu
Website: <http://www.umich.edu/~glblfem>**

© Regents of the University of Michigan, 2021

Lisa McCorkell, MPP, is the co-founder of the Patient-Led Research Collaborative (PLRC), a group of people with Long COVID who conduct research on Long COVID. She has presented PLRC's work to Congress, NIH, CDC, the President's COVID-19 Health Equity Task Force, and more, and has co-authored several research papers and chapters on Long COVID. She is a policy expert, with a background in social safety net, public health, labor policy, advocacy, writing, and research. She has a Masters of Public Policy from UC Berkeley and a Bachelor of Arts in Political Science from UCLA.

Abigail Dumes is a medical and cultural anthropologist and an assistant professor in the Department of Women's and Gender Studies at the University of Michigan. Dumes received her PhD in sociocultural anthropology from Yale University, and her first book, *Divided Bodies: Lyme Disease, Contested Illness, and Evidence-Based Medicine*, was published by Duke University Press (2020). Her ongoing research explores the relationship among gender, contested illness, infectious disease, and environmental risk in the United States; she is working on a new project on Long COVID.

Abby Dumes: Hi, my name is Abby Dumes. My pronouns are she/her. I'm a white woman with a purple and blue floral print top. I've got bird-shaped turquoise earrings and brown hair in a braid. Behind me to my left shoulder is a red framed painting, and to my right are bookshelves.

Lisa McCorkell: And I am Lisa McCorkell. I use she/her pronouns. I am a white woman with brown hair that's down. I'm wearing a white and black floral print shirt and my background is blurred out, but you can see a little bit of orange in the background.

AD: Lisa, thank you so much for being here and being willing to share your story with the Global Feminisms Project. I'm going to quickly introduce you and then we'll launch into our questions. Lisa McCorkell is the Co-founder of the Patient-Led Research Collaborative, or PLRC,¹ a group of people with Long COVID² who conduct research on Long COVID. She has presented PLRC work to Congress, NIH (National Institutes of Health),³ CDC (Centers for Disease Control and Prevention),⁴ the President's COVID-19 Health Equity Task Force, and more. And has co-authored several research papers and chapters on Long COVID. She is a policy expert with a background in social safety net,⁵ public health, labor policy, advocacy, writing, and research. She has a Master's of public policy from UC Berkeley⁶ and a Bachelor of Arts in political science from UCLA.⁷ So, I think we'll start with where your story

¹ PLRC, also known as the Patient-Led Research Collaborative, is an organization consisting of medical researchers who are motivated to investigating the effects of COVID-19. ("About the Patient-Led Research Collaborative." Patient-Led Research Collaborative. <https://patientresearchcovid19.com/>. Accessed 12 September 2022.)

² Long COVID is a condition in which individuals affected by COVID test positive for weeks, or even months, after the first onset of illness and report long-lasting symptoms after as well. ("What is long COVID?" Greater Than COVID. https://www.greaterthancovid.org/videos/what-is-long-covid/?gclid=CjwKCAjwvNaYBhA3EiwACgndginkmKmFOVHJtNVDW0dzks5GRIQqbCh7IHrS1EV2QyOrp-t6b7bUABoCx1kQAvD_BwE. Accessed 5 September 2022.)

³ NIH, also known as the National Institutes of Health, is a section of the US Department of Health and Human Services that is dedicated specifically to medical research. ("Who We Are." National Institutes of Health. <https://www.nih.gov/about-nih/who-we-are>. Accessed 5 September 2022.)

⁴ The CDC, also known as the Centers for Disease Control and Prevention, is an organization dedicated to protecting the health of the US population by investigating public health threats. ("About CDC." Centers for Disease Control and Prevention. <https://www.cdc.gov/about/index.html>. Accessed 5 September 2022.)

⁵ Social Safety Net is help provided to families and individuals who might be experiencing poverty via programs such as fee waivers and free school lunches. ("Social Safety Net." Wikipedia. https://en.wikipedia.org/wiki/Social_safety_net. Accessed 5 September 2022.)

⁶ UC Berkeley, also known as the University of California Berkeley, is a public higher education institution located in Berkeley, California. Many research centers and institutes are part of the University. ("University of California, Berkeley." Wikipedia. https://en.wikipedia.org/wiki/University_of_California,_Berkeley. Accessed 5 September 2022.)

⁷ UCLA, also known as the University of California Los Angeles, is a public university located in Los Angeles, California. UCLA is known for being a research university and is also regarded as one of the best universities

begins, if you think about where you are today—we'd like to hear a little bit about how you would depict the journey that brought you to where you are now.

LM: Sure, yeah. So, I think—kind of every step of my life has really brought me to this point, which makes sense, but I never would have guessed that this is where I would end up: as the co-founder of a Patient-Led Research Organization on Long COVID—mainly because COVID didn't, you know, wasn't a thing before two years ago.

AD: Exactly.

LM: But I can—I'd say yeah I can just start from the beginning.

AD: Sure.

LM: I think a lot of what my background really stems from is—from both my, you know, personal and professional experiences. So, when I was 12 years old, I was diagnosed with celiac disease.⁸ I was very active at that time, even for 12, on discussion forums on celiac and kind of how to adjust to a gluten free lifestyle. So—and really got a lot of support out of those forums. My mom was diagnosed with multiple sclerosis⁹ around that time as well, and went on disability.¹⁰ And just generally, you know, had a lot of medical issues, chronic illnesses,¹¹ a lot of unexplained chronic illnesses in my family. And so, that's kind of, I think, the backdrop personally, and then I went to college. Initially, I was interested in

in the world. ("University of California, Los Angeles." Wikipedia.

https://en.wikipedia.org/wiki/University_of_California,_Los_Angeles. Accessed 6 September 2022.)

⁸ Celiac disease is a chronic illness that affects the digestive system. The intake of gluten has an adverse effect on the small intestine and can result in digestive problems in the long run. ("Celiac Disease." NIDDK.

<https://www.niddk.nih.gov/health-information/digestive-diseases/celiac-disease#:~:text=Celiac%20disease%20is%20a%20chronic.all%20the%20nutrients%20it%20needs>. Accessed 6 September 2022.)

⁹ Multiple Sclerosis, also known as MS, is a disease that affects the Central Nervous System (CNS). MS causes the immune system to attack the CNS and can result in symptoms such as numbness and mood changes, or symptoms as severe as paralysis. ("What is MS?" National Multiple Sclerosis Society.

https://www.nationalmssociety.org/What-is-MS?gclid=Cj0KCQjw39uYBhCLARIsAD_SzMSyQERKiq8_oHycv7tFPUJS4zNncnhLpcW8GSyOgAVIA_2X_O-gdNoaAhqHEALw_wcB. Accessed 6 September 2022.)

¹⁰ Social Security Disability Insurance, also referred to as disability, is a government program that helps disabled individuals and their families via government benefits. ("Disability Benefits." SSA.

<https://www.ssa.gov/benefits/disability/>. Accessed 6 September 2022.)

¹¹ Chronic illnesses are illnesses that have a long-lasting impact (usually 1 year or more) on an individual's health and demands regular medical care. Chronic illnesses can also have a significant impact on an individual's daily life. ("About Chronic Diseases." CDC.

<https://www.cdc.gov/chronicdisease/about/index.htm>. Accessed 6 September 2022.)

neuroscience,¹² and kind of using my skills in science and biology, but decided to major in political science, mainly because I was really interested in how politics impacted people's day to day lives. I had seen how policies and politics impacted my mom's ability to get on disability benefits—

AD: Mm-hmm.

LM: —and just start various access to different benefits. My first job out of college was as a financial counselor. I helped people with their budgets and credit scores. And then I went to work at a nonprofit employment law center that focused on gender and racial equality in the workplace, as well as stable scheduling for hourly workers.

AD: Mm

LM: So, all of that experience kind of really showed me—and continued to show the impact of policies on people's lives and ability to, you know, have equal and equitable outcomes. But decided from there I really wanted to do more with that. So, went to graduate school to get my Master's in public policy. While I was there, I took a few health equity classes—kind of just by chance. I was just interested in the topic of social determinants of health,¹³ but really wasn't focusing on health policy itself.

AD: Mm-hmm.

LM: I was more a generalist and kind of interested in a lot of different areas of policy. That was—so I graduated in May of 2020, and I got COVID in March of 2020. This was very early on, right before the lockdown—that's when I had my first symptoms. And at that point, I joined the Body Politic COVID-19 support group¹⁴ about a month after I started experiencing symptoms. Mainly because it was—you know, at that time—there wasn't much discussion of these prolonged symptoms of COVID. It was—you know, you're either hospitalized or you have a very severe course of illness. Or, if you have a mild version, you recover within two weeks. So, once I realized, you know, that wasn't my personal health

¹² Neuroscience refers to the nervous system and the study of how the nervous system functions. ("About Neuroscience." Georgetown University. <https://neuro.georgetown.edu/about-neuroscience/>. Accessed 6 September 2022.)

¹³ Social determinants of health refer to the conditions in which people live, work, travel, etc. that can have an impact on their health. ("Social Determinants of Health." Healthy People 2030. <https://health.gov/healthypeople/priority-areas/social-determinants-health>. Accessed 6 September 2022.)

¹⁴ The Body Politic COVID-19 support group is a group dedicated to helping individuals who have been addicted by COVID-19 via emotional support and a community of individuals who have experienced similar problems. ("COVID-19 Support Group." Body Politic. <https://www.wearebodypolitic.com/covid-19>. Accessed 6 September 2022.)

journey, and I was having these prolonged symptoms and actually feeling a lot worse as time went on. Joined the support group, and founded Patient-Led Research Collaborative from that. I can talk a little bit about kind of where—how we've come to be from there if that would be useful?

AD: Yeah, that'd be great. Let's keep talking about your work with the PLRC.

LM: Yeah. So, we all came together in April of 2020. All joined the Body Politic support group, and we saw this need. Everyone was sharing their experiences and their—these prolonged symptoms that—you know, again, the government and media, no one was really talking about—and sharing different treatments that they're trying and different research they're coming across. And we saw this need to compile that information and see if there was any trends occurring, if people are experiencing the same symptoms, and just really tried to compile all this information. So, a few of us who had had some kind of research backgrounds came together, put together a survey, and produced the first research on Long COVID. We did it in less than a month, put out the survey, and then did a very quick analysis and did a google doc where we put this report, and it was published May 11th of 2020, and that was really the birth of Patient-Led Research Collaborative—unbeknownst to us that it would be where it's at now today. From that report, we started getting some media attention on what Long COVID was, and we connected with the CDC, and a few other government organizations that wanted to hear more about the experience, and really started recognizing this as like, “Oh, this could be an issue if there's this big subset of people that are experiencing these prolonged symptoms.”

AD: Mm-hmm.

LM: And of course, we know that—you know—really, post-viral illness¹⁵ and Long COVID isn't new. It's just—you know—all post-viral illnesses have existed since really viruses have existed. But, unfortunately at the time, people with post-viral illness were not being listened to, and their warnings about this possibility of Long COVID weren't heeded. And so, from there we—you know—we got a lot of interest from different researchers, and from different government orgs [organizations] trying to learn more about the Long COVID experience, and trying to hear what symptoms we were experiencing. So, we did a follow up survey that was more expansive. We put a preprint of that up in December of 2020, and it was published in THE LANCET eClinicalMedicine¹⁶ in July of 2021. And that documented

¹⁵ Post-viral illness, or post-viral syndrome, is an illness in which an individual experiences long-lasting effects of a viral illness. Symptoms can include fatigue, headaches, and more. ("An Overview of Post-viral Syndrome." SMA. <https://sma.org/post-viral-syndrome/>. Accessed 6 September 2022.)

¹⁶ eClinicalMedicine is an online medical journal published by The Lancet. These journals are open to the public and are meant to help researchers find issues and help public health problems across the world.

the over 200 symptoms of Long COVID, and the trajectory of symptoms over seven months of illness at the time. And from there, we just, you know, continued to do various research projects. Consulting on Long COVID research as it started popping up, and researchers started paying attention to it. Started advocating for policies that support people with Long COVID and all post-viral illnesses. And in terms of my interaction with Patient-Led Research Collaborative, and my involvement—I was doing all of that work on the side. I had had a full-time job working on SNAP policy¹⁷ in California. And so, anything I was able to volunteer was what I was doing with PLRC until May of this year. We received funding that enabled me to go full time with Patient-Led Research Collaborative, which is—

AD: Oh, wow. Congratulations.

LM: Thank you. Yeah. So, now we're scaling up, we have a few new projects that we're launching. And yeah, just more and more attention is being paid to Long COVID.

AD: Mm-hmm.

LM: There's still a lot of narratives that we're, you know, having to contradict that are misinformation and—But, we've come a long way and in two years, and I think a lot of it has to do with our early work, as well as many of the other patient-led organizations that have come out of Long COVID.

AD: You mentioned that you initially started sort of under the umbrella of Body Politic. At what point did you become your own entity? And then maybe describe a little bit, as you mentioned, some of the collaboration between and among groups.

LM: Yeah. We—I mean—what's interesting is that even now we still work within the Body Politic slack¹⁸ support group. So, all of our work is done pretty much asynchronously through the Body Politic slack group.

AD: I see.

("eClinicalMedicine Homepage." The Lancet. <https://www.thelancet.com/journals/eclinm/home>. Accessed 6 September 2022.)

¹⁷ The Supplemental Nutrition Assistance Program, also known as SNAP or CalFresh, is a government program that helps families and individuals buy food by providing a monthly stipend. ("Benefits of CalFresh." SLO Food Bank. https://www.slofoodbank.org/benefits-of-calfresh/?gclid=Cj0KCQjw39uYBhCLARIsAD_SzMTYw-ZUq0u2pIno6aahhJPh_exlNIM82HLZyzLOgkaA2LveSSalhkaArO5EALw_wcB. Accessed 6 September 2022.)

¹⁸ Slack is an app that allows groups of individuals and organizations to communicate with each other via messages. ("What is Slack?" Slack. <https://slack.com/help/articles/115004071768-What-is-Slack->. Accessed 6 September 2022.)

LM: But we became our own –I think kind of group—once we started receiving some funding for the research specific group.

AD: Mm-hmm.

LM: So, we started an LLC,¹⁹ and that was probably in like July or August of 2020.

AD: Okay.

LM: So, still pretty early on.

AD: Yeah, pretty early on. Mm-hmm.

LM: Most of the advocacy that we do is in partnership with Body Politic. We really tried to, you know, if any of the policy proposals are, when we're identifying needs of the community, it's sourced from the support group. And we have very close collaborations with many of the other advocacy groups—That we've kind of just found each other and are trying to support each other as best we can.

AD: That's really helpful. Thank you. I guess we'll move on to thinking about this work in the context of feminism, and if we could just pick your brain a bit about how you understand the term feminism. What it means to your work—if it means anything to your work? If you consider yourself a feminist? Mapping that out would be helpful.

LM: Yeah. Sure. So, I mean how I understand the term, feminism, is largely, I think that, by definition, equal rights and opportunities for all genders, but also equity within genders. So, you know, within different races and ethnicities. Within different disability statuses. You know, in my view, a feminist is not necessarily someone who wants equal rights between white able-bodied woman and white able-bodied men. You know, it's more intersectional than that. And, particularly within an illness like Long COVID.

AD: Mm-hmm.

¹⁹ A Limited Liability Company, or LLC, is a business that has multiple owners, also referred to as members, that all equally own the company. ("What is an LLC?" NOLO. <https://www.nolo.com/legal-encyclopedia/what-is-a-limited-liability-company.html>. Accessed 6 September 2022.)

LM: --and other post-viral illnesses that do seem to impact women and transgender people more than men, feminism has really played a critical role.

AD: Mm-hmm.

LM: Even within our group, Patient-Led Research Collaborative, we're all—it's all co-founded, and leadership is all women. So, it is very important to us and we—you know—take that very seriously, and have seen the severe downsides of a lack of feminism, and a lack of focus on—really equity, and a lack of focus on women in the medical field.

AD: Mm-hmm.

LM: So, an example of that is: the role of reproductive health and sex hormones²⁰ is severely lacking

AD: Mm-hmm.

LM: —in any research on Long COVID.

AD: Mm. Mm-hmm.

LM: We're not seeing—you know—if we see surveys: they're not asking about menstrual cycle changes—

AD: Mm. Mm-hmm.

LM: —or any type of menstrual symptoms. But, that's really one of the biggest things that we're seeing people experience. That's one of my main symptoms. I developed premenstrual dysphoric disorder (PMDD)²¹ after Long COVID.

AD: Mm.

²⁰ A sex hormone is a hormone that is produced by any of the sex organs, such as the ovaries and testes, that impacts the reproductive system. ("Sex hormone Definition & Meaning." Merriam-Webster. <https://www.merriam-webster.com/dictionary/sex%20hormone>. Accessed 6 September 2022.)

²¹ Premenstrual dysphoric disorder is a condition in which an individual's hormone levels fall as ovulation ends, and as a result can cause irritability and depression. ("Premenstrual dysphoric disorder." Office on Women's Health. [https://www.womenshealth.gov/menstrual-cycle/premenstrual-syndrome/premenstrual-dysphoric-disorder-pmdd#:~:text=Premenstrual%20dysphoric%20disorder%20\(PMDD\)%20is, days%20after%20your%20period%20starts](https://www.womenshealth.gov/menstrual-cycle/premenstrual-syndrome/premenstrual-dysphoric-disorder-pmdd#:~:text=Premenstrual%20dysphoric%20disorder%20(PMDD)%20is, days%20after%20your%20period%20starts). Accessed 8 September 2022.)

LM: That is *never* asked about. A lot of people are experiencing perimenopause.²² They're having difficulties becoming pregnant.

AD: Mm.

LM: You know that's—These are all things that are severely understudied and—so, it's critical to, in this work, be a feminist. And-- in order to ensure that research is representative.

AD: Mm-hmm. Mm-hmm. Mm-hmm.

LM: And that it's actually capturing people's experiences.

AD: Mm-hmm.

LM: So yes, I definitely consider myself a feminist. And we try to incorporate intersectional feminism²³ in our work, and particularly our advocacy, as much as possible.

AD: Thank you so much. So, you mentioned in the beginning a little bit about your own symptomatic experience, and then just a little bit now. Would you mind sharing a little bit more about that journey? And maybe experiences you had in a clinical setting. Thinking about gender and how gender impacts clinical experiences and—

LM: Yes.

AD: —Long COVID more generally.

LM: Yes, absolutely. So, I was—so, I first got sick March 14th, 2020. Had initially mild illness. But within about three to four weeks into my illness I was unable to walk a block without having severe shortness of breath, being very fatigued, bedbound for the rest of the day. And this was--you know, pre-COVID: I was a half marathon runner, and this was very

²² Perimenopause is the period in which an individual's body transitions from menstruation to menopause ("Perimenopause." Mayo Clinic. <https://www.mayoclinic.org/diseases-conditions/perimenopause/symptoms-causes/syc-20354666>. Accessed 8 September 2022.)

²³ Intersectional feminism is recognizing the different types of inequalities among women (and all people) that arise from the intersections of different oppressive forces (sexism, racism, classism, ableism, heterosexism, etc. ("Intersectional feminism: what it means and why it matters right now." UN Women. <https://www.unwomen.org/en/news/stories/2020/6/explainer-intersectional-feminism-what-it-means-and-why-it-matters#:~:text=Kimberl%C3%A9%20Crenshaw%2C%20an%20American%20law,a%20recent%20interview%20with%20Time>. Accessed 8 September 2022.)

different than what I had experienced before. At the time, the care that I received it was—I wouldn't say I was dismissed at that time. It was more just like—my providers didn't know what was happening. But, they were very clear with the fact that they didn't know.

AD: Mm-hmm. Mm-hmm.

LM: And that this was all very new.

AD: And did you have a positive test at the time? I know that can be a limiting factor.

LM: Right. Yeah. No, I wasn't able to get a test, because I didn't have a fever. And you needed to have cough, shortness of breath, and fever in order to get a test.

AD: I see.

LM: So at the time, you know—my provider clinically diagnosed me with COVID. But I wasn't able to get a test.

AD: Mm.

LM: But that—kind of bit me later on.

AD: Right.

LM: And I started, you know—I would have a lot of brain fog,²⁴ fatigue, these periods of shortness of breath, and tachycardia.²⁵ But, you know, after a couple months I started feeling a little better, I felt like I was doing a very, very slow recovery.

AD: Mm-hmm. Mm-hmm.

²⁴ Brain fog is a symptom of COVID-19 and is defined as slowed neurological processes, which can mean attention problems and slowed thinking. ("COVID-19 and 'Brain Fog': What to Expect and How to Manage." GoodRx Health. <https://www.goodrx.com/conditions/covid-19/covid-brain-fog>. Accessed 8 September 2022.)

²⁵ Tachycardia is defined as having a heart rate over 100 bpm. A high heart rate can lead to health issues, like heart failure, in the future if left untreated. Symptoms can include chest pain and shortness of breath. ("Tachycardia." Mayo Clinic. [https://www.mayoclinic.org/diseases-conditions/tachycardia/symptoms-causes/syc-20355127#:~:text=Tachycardia%20\(tak%2Dih%2DKAHR,as%20a%20response%20to%20stress](https://www.mayoclinic.org/diseases-conditions/tachycardia/symptoms-causes/syc-20355127#:~:text=Tachycardia%20(tak%2Dih%2DKAHR,as%20a%20response%20to%20stress). Accessed 8 September 2022.)

LM: But then, in August of 2020, I pushed myself more than I had. Before, I did this exercise class that was *way* more than what I had done in the past. And, I had this severe tachycardia, palpitations, shortness of breath--to the point where I really felt like—you know—something could be wrong with my heart—

AD: Mm-hmm.

LM: —You know? Or something's *definitely* wrong. So, I went to the ER, and the provider there not only said that I *never* had COVID, but he also said that my symptoms were anxiety²⁶ and nothing else. But didn't even then give me treatment for the anxiety that he diagnosed me with.

AD: Mm.

LM: He just sent me home and said, "You know, you need to just calm down, and then you will have--your symptoms improve."

AD: Mm-hmm.

LM: That didn't happen, unsurprisingly. I continued to have symptoms, but what that *did* result in was me being very skeptical, to this day, about seeking medical care.

AD: Mm-hmm. Mm-hmm.

LM: It is now a fairly terrifying experience going to a provider when you know that there's the option of them dismissing you—

AD: Mm-hmm. Mm-hmm.

LM: And not taking your concern seriously.

AD: Mm-hmm. Mm-hmm.

LM: And also, you know, especially him saying I never had COVID: just completely dismissing my experience.

²⁶ Anxiety can manifest as a disorder in which an individual feels chronically stressed or nervous. Some common symptoms include tensed muscles and avoidance. ("What are Anxiety Disorders?" American Psychiatric Association. <https://psychiatry.org/patients-families/anxiety-disorders/what-are-anxiety-disorders#:~:text=Anxiety%20is%20a%20normal%20reaction,involve%20excessive%20fear%20or%20anxiety>. Accessed 8 September 2022.)

AD: Mm-hmm.

LM: And something I knew to be true. And that—yeah. That's, unfortunately, something that's not a unique experience. I think that the vast majority of people with Long COVID, *particularly* women, and *particularly* women of color, are—even to this day—experiencing this dismissal. Because of, I think it's more lack of awareness of these symptoms—

AD: Mm-hmm.

LM: —and a lack of awareness of post-viral illness generally.

AD: Mm-hmm.

LM: But the reason there is that lack of awareness is because it's largely *women* that are impacted. And so it's been understudied; it's been historically dismissed.

AD: Mm-hmm. Mm-hmm.

LM: And yeah. So, I mean that's one of the biggest fights that we have in Long COVID is just this recognition. This *need* for recognition that our symptoms are *real*. That we deserve treatment. That we deserve proper care. And also that providers, you know—if you don't know what's going on—it's okay to say, “I don't know.”

AD: Mm-hmm. Mm-hmm.

LM: You don't need to give a diagnosis, you know—a mental health diagnosis—if it's not. You know—

AD: Mm-hmm.

LM: —haven't done the proper screenings to get to that diagnosis. Yeah. I'll pause there.

AD: Really helpful. So, that was August 2020. What happened after that?

LM: Yeah. So, that's when I really turned back to the support groups, and going online for information. And, I recognized that, “Oh, what might actually be happening right now is a POTS attack.”

AD: Mm. Mm-hmm.

LM: Or, Postural Orthostatic Tachycardia Syndrome,²⁷ that seem to be very—you know—a lot of people with Long COVID were having those same symptoms. Getting that diagnosis, it's often onset by a virus. And so I did kind of an at home test, where you stand up and see how much your heart rate goes up within a certain amount of time, and I realized like, "Oh, that might be it."

AD: Mm.

LM: And, so I kind of had a self-diagnosis, at that point, and tried to learn to manage it based off of people's tips, and just what they were sharing online. And then, it took another few months for me to feel comfortable going back to a provider. And I tried to find a provider that was a woman, and who had a bit of experience in POTS, and some of the other post-viral illnesses. And so, once I was able to go to her, she did an official test and gave me a POTS diagnosis. And it took, you know, even at that point, I hadn't identified the PMDD, or Premenstrual Dysphoric Disorder Symptoms, that I was describing. And I was never asked about those symptoms by any provider, any type of mental changes or mood changes around my period. So, it took me longer to identify this kind of pattern that I was experiencing of worsening symptoms a week before my period, particularly very severe mood symptoms.

AD: Hmm.

LM: And so that took another year, I would say, to get that diagnosis. But from there my symptoms kind of had a relapsing--I don't want to say remitting, because I never went back to full remission.

AD: Mm-hmm.

LM: But just more stabilizing, kind of back and forth until I got the second COVID vaccine, which actually helped to improve my symptoms, and I went to a higher baseline.²⁸

²⁷ Postural Orthostatic Tachycardia Syndrome, or POTS, is when an individual's blood flow isn't being regulated by their automatic and sympathetic nervous system. Symptoms can include fainting and an increase in heartbeat. ("Postural Orthostatic Tachycardia Syndrome (POTS)." Cleveland Clinic. <https://my.clevelandclinic.org/health/diseases/16560-postural-orthostatic-tachycardia-syndrome-pots>. Accessed 8 September 2022.)

²⁸ Baseline, in medicine, refers to a patient's condition before and after treatment. Baseline testing allows healthcare providers to see how treatment affects their patients. ("Baseline Testing." WorkplaceTesting. <https://www.workplacetesting.com/definition/1237/baseline-testing>. Accessed 8 September 2022.)

AD: Mm-hmm. Mm-hmm.

LM: Still not back to you know before—

AD: March 2020?

LM: —yeah. But have been fairly improved since then I'd say. I still deal with POTS symptoms but they're—you know, often pretty well managed. And then I'm still trying to figure out the PMDD, and what helps with that. So, yeah: it's interesting. I mean I'm able to have a full-time job—probably wouldn't if it was in person.

AD: Mm. Mm-hmm. Mm-hmm. Mm-hmm.

LM: That would be very tough for me. But I have a very mild version of Long COVID.

AD: Mm. Mm-hmm. Mm-hmm

LM: And it still impacts—you know, my hour to hour. So, it's—yeah. Long COVID can really be extremely severe. I'm very grateful for the amount of you know, health, that I have *now*, and trying to use that to help advocate for other people.

AD: Yeah, that's really interesting. So, do you have strategies, given the extent to which is still impacts your day, do you have strategies to minimize that? I know resting and pacing have been really important for some. Is that something that you're mindful of throughout the day?

LM: Yes, definitely resting and pacing. Trying not to have too much going on in one day, and having breaks throughout. If I feel—You know, if I start feeling symptoms coming on, which, it is interesting, I can very easily tell when they're coming.

AD: Mm.

LM: Just trying to—you know, take a break immediately and do radical rest. I always—

AD: Ooh, I like that: radical rest. Have you used that term before? Or is that a term that you use?

LM: Yeah! Yeah, it's important to do.

AD: Right.

LM: Because I think a lot of people think resting is—you know: you can watch TV, you can read, you can do that type of stuff.

AD: Right.

LM: But really what's needed is like *no* sensory input.²⁹

AD: Mm-hmm. Mm-hmm. Mm-hmm.

LM: And just very radically like—just laying down and not doing anything, and prioritizing that.

AD: Mm-hmm. Yeah, that seems like a really important distinction.

LM: Yeah.

AD: Helps frame it, I think.

LM: Yeah. But yeah, I always have a big thing of water next to me, which is helpful for POTS: is increasing fluid and salt intake. And so, those are the biggest things that I do: is trying to manage salt through those types of—Er, sorry—manage POTS through lifestyle modifications, and then just the pacing is a *huge* one that's always important to do.

AD: Mm-hmm. So I think we talked a little bit in the beginning about collaboration between and among Long COVID groups. Has there been work internationally in the context of your group? And, if so, what does that international, transnational collaboration look like?

LM: Yeah. So, we have—Long COVID groups have popped up in many, many countries, and we try to maintain relationships with all of them. Body Politic itself is international.

AD: Mm. Mm-hmm. Mm-hmm.

²⁹ Sensory input is the response of a sensory organ when stimulated. Stimuli can be anything that can be observed, touched, heard, smelled, and tasted. ("Sensory Input." AlleyDog. <https://www.alleydog.com/glossary/definition.php?term=Sensory+Input>. Accessed 8 September 2022.)

LM: So—you know, anyone from any country can join. Our organization—we have members from—I think it's like—I think 10 countries is what we—is what our membership is from.

AD: Hmm.

LM: We have a total of 45 volunteers.

AD: Wow.

LM: I think over 10 countries or so. And yeah. So, there is a—I mean, you know Long COVID is impacting every country. It impacts, you know, 10 to 30% of COVID cases, so it has really big impacts across the world. And where we've seen a lot of our partnerships is from when we are trying to distribute our survey.

AD: Hmm.

LM: We tried really hard to partner with other countries groups so that they can share that with their membership. We had our last survey translated into—some—I think it was 16 languages. Really trying to get more diverse respondents—

AD: Mm-hmm.

LM: —and capture the experience of people in other countries. And yeah, I think it's really important to see the reaction in different countries of governments' response to Long COVID. Of—you know—how people are—If people have access to adequate care.

AD: Mm-hmm. Mm-hmm.

LM: And so, that's all been really important for us. And a lot of our work that we're starting, with our new funding, is really trying to focus on that even more. To focus on the international aspect more. Because, so much, you know, research generally—but, you know, Long COVID for what we've seen has been focused on U.S. (United States), and it's very Eurocentric³⁰ as well.

³⁰ Eurocentric refers to anything that starts with Europe or European culture as the focus point. ("Eurocentric Definition & Meaning." Dictionary. <https://www.dictionary.com/browse/eurocentric>. Accessed 8 September 2022.)

AD: Right.

LM: So you know, trying to more look at, you know—what's going on in other countries. And how can we ensure that if there are treatments that become available, that they'll be available to *everyone* in the world, you know, that's a global thing, that's accessible. So, that's something we're working—we're trying to work with more, and that will include a lot more partnerships with some of the orgs in other countries.

AD: Have you seen any of the gendered patterns we were talking about in the U.S. also play out in other settings? Are there similarities or differences, and can you trace a few of those? Or—I should say gendered and intersectional.

LM: Yeah, I definitely—definitely similar, you know, dismissive type of experiences from providers. But you know, we definitely see that in Europe, and we have a large contingent in the UK.

AD: Mm-hmm.

LM: And yeah, from the experiences that we've heard from other countries, like more low- to middle-income countries: it seems to be playing out there as well, I think—you know, it sounds like probably to a more severe degree, but that's part of what we're—one of the studies that we want—are *going* to launch—Is a quality of life survey for people with Long COVID, and from low- to middle-income—

AD: Mm. Mm-hmm.

LM: countries looking at that question, you know looking at people's experiences, in receiving care, and their symptoms, and if there's different--you know—types of symptoms and severity across genders, you know, income strata,³¹ all of that.

AD: Mm. Mm-hmm. Mm-hmm. Wow, that seems like such an important contribution, and a really understudied dimension. Has that survey already launched this, or is it sort of in the works?

LM: In the works. Yeah. Hopefully in the next few months we'll get it launched.

³¹ Income strata refers to people making up a society in terms of their average income or wealth level; the “strata” are the different levels, which are defined by processes of economic stratification (“Economic stratification.” Wikipedia. https://en.wikipedia.org/wiki/Economic_stratification. Accessed 8 September 2022.)

AD: Wow. I'll be really curious to see. At least in the, you know—the social science work on chronic illness, it's a *very* understudied part of literature, and so it'll be really helpful to see what you find out. Maybe we can talk a little bit about—sort of—personal and organizational sort of—future orientations. So sort of where you see things going from here for you? Even down to how you sort of navigate the present and the future with risk management. Having experienced this, does it change the way that you are navigating your life in a continued pandemic world? And maybe some more of the projects that PLRC might take on in the future.

LM: Yeah. It's a tough question, I think, because, as PLRC, we've formed seemingly kind of out of thin air, kind of just by chance, and didn't have a strategy from the beginning of like, "We're building an organization that's gonna be sustainable for years."

AD: Mm-hmm. Mm-hmm.

LM: And so, we've kind of just been going based off of opportunities that have arisen, and this, you know, dire need for this type of work. The current funding we have is for a year.

AD: Okay.

LM: So, it's you know unclear, beyond that. But, we know that Long COVID's not going away.

AD: Right.

LM: More research will be needed; more advocacy will be needed. So, you know, potentially—you know *likely* will still be around, and be working on other projects. But yeah. I mean right now—so the projects that we're standing up: it's the lower to middle income country quality of life I talked about.

AD: Mm-hmm. Mm-hmm.

LM: Our biggest one is a research fund—So, we're actually re-granting some of the funds that *we're* getting. We're gonna identify projects that are really—hopefully, on the cutting edge of finding out what is actually behind Long COVID, and other post-viral illnesses, and what are some viable treatments for that. So we're going to have a round of accepting proposals, and we'll—we have a patient panel that we formed, that is just *really* incredible. Patients in—that either have Long COVID, or another illness like ME/CFS, which is Myalgic

Encephalomyelitis or Chronic Fatigue Syndrome,³² POTS, which I mentioned earlier—which is what I have—and other illnesses. So people with the lived experience of one of these illnesses, as well as a professional experience in some type of research area. So, we gathered this patient panel, and they'll help us identify which projects to fund that really have the most promise in helping us find answers.

AD: Mm.

LM: So we're very excited about that. And another one that we're looking at that we think is *very* important for informing pandemic policy in the future is looking at reinfections, and the role that those play on both you know, people with—that currently have Long COVID: How does getting reinfected with COVID impact their symptoms? But also, if you, you know, *had* COVID, did *not* develop Long COVID, and then are reinfected: what are your chances of developing Long COVID after that?

AD: Mm-hmm.

LM: And seeing that there's an increased chance, which I think is *not*, you know, clearly has not been considered—

AD: Mm-hmm.

LM: —in pandemic policy, you know—When we're thinking through the possibility of, you know, COVID being “normalized” quote-unquote, or this like, “return to normal.” It's this assumption that people will just keep getting reinfected, and we'll have to deal with several reinfections a year—

AD: Mm-hmm.

LM: —without considering the very real possibility that a large proportion of those people will get Long COVID.

AD: Mm-hmm.

³² Myalgic Encephalomyelitis or Chronic Fatigue Syndrome or ME/CFS is a condition that causes excessive fatigue/tiredness and trouble sleeping, concentration, or thinking. ("Myalgic encephalomyelitis or chronic fatigue syndrome (ME/CFS)." NHS. <https://www.nhs.uk/conditions/chronic-fatigue-syndrome-cfs/#:~:text=Myalgic%20encephalomyelitis%2C%20also%20called%20chronic,%2D20s%20and%20mid%2D40s..> Accessed 8 September 2022.)

LM: So, you know, trying to measure that, and come to figure out what kind of impact reinfections are going to play, I think, will be *hugely* important for the future. So, those are some of the projects that we're starting, and you know, I imagine that there'll be more, you know, hypotheses that we want to tackle in just the next few months

AD: Mm-hmm.

LM: Or you know when in the next year, but yeah. It's kind of a big question mark. I think we've been we've been very *reactive* as an organization, more so than you know, planning it out.

AD: Mm-hmm. Mm-hmm.

LM: Because, ideally we wouldn't need to exist as an org. So we're not planning for long-term sustainability, although it might be smart at this point to do so, unfortunately.

AD: So with that information, how do you process that in your own personal life, navigating sort of risk:benefit analysis of living in a pandemic world? Are you more cautious, having been through what you've experienced, and take greater steps to avoid reinfection?

LM: Yeah—

AD: Or has it framed decisions in a different way?

LM: Yeah, absolutely. I mean, I would say, you know, I'm definitely the more cautious of my friends outside of, you know, the Long COVID community. And yeah, I think like seeing it firsthand, experiencing it firsthand, can really make people realize what the risks are and—

AD: Mm-hmm. Mm-hmm.

LM: —So yeah, I have not returned to “normal.” And that's, not just because my body hasn't returned to normal it's, you know, just that it's not it, it really is not worth the risk to myself, nor other disabled people that are at risk if I *do* decide to go into public unmasked. Or you know, do some riskier activities. So yeah, I limit my travel, I stay masked in public, I don't do indoor dining, and I, I really don't see much of that changing anytime soon.

AD: Mm-hmm.

LM: I think that this is, you know, my new normal.

AD: Mm-hmm. Mm-hmm.

LM: And I will always be you know kind of a higher risk now. And—yeah. The removal of the mask mandates, I think in particular, was more of what has had an impact on my life, because I used to feel like fairly comfortable going to the grocery store and taking care of my day-to-day needs.

AD: Mm-hmm.

LM: And now that becomes a fairly risky situation.

AD: Mm-hmm.

LM: You know, even if I'm masked, the fact that a lot of people around me are not [masked] during a surge is very risky.

AD: Mm-hmm.

LM: So it's definitely, you know, this experience has absolutely, I'm sure, you know, changed my risk assessment and, you know, what I'm willing to do to avoid a reinfection—

AD: Mm-hmm.

LM: —because I know what the potential consequences are.

AD: Mm-hmm. Mm-hmm. It's really illuminating. I want to go back to the idea of radical rest, and situate it within sort of societal expectations of work and rest, and what you think might be some of the equity limitations in a solution to feeling unwell that might not fit with societal expectations.

LM: Yeah, that's a great question, and a huge question. So in our survey, we found that two-thirds of our respondents were either completely unable to work, or had to reduce their hours. I think that a lot of it-- based off of from, you know, what we've heard from patients, and what we've experienced ourselves-- is not that people are actually completely unable to work, but they're not receiving the accommodations that they need to be able to work in our society, right? And the really harsh demands and very strict timeframe that society has set up work. I think that's one of the best things about PLRC is that we communicate largely asynchronously. So, whenever, you know, we try to limit meetings as much as possible. So people don't have to be, you know, feeling well, and be expected to feel well enough for a

phone call all, at the same time. So you participate when you're able to, you know, having long deadlines. You know—not having short turnaround times. Allowing people to work in the middle of the night if they need to. And just really focusing on, “what are people's access needs?” in order to participate and trying to meet those as best as possible. And so that's how we've run our organization, and we have done a lot over the last two years, right? It's not that, you know, I think we have created this model of work that is-- where people can contribute when they're able to and you know, we have this really amazing work product, and we're able to make a lot of change in the world, but it's on a different timeline and using different structures than what most of the capitalist society³³ adheres to and thinks is required. And yeah. I mean—we'll have—a lot of our volunteers will go through relapses. Will be crashed for weeks, and we, you know—we never want people to work through that: health is the priority, right? That's the priority for us as people—as well-being. And unfortunately, that's not the priority of most of society is: it's not well-being; it's productivity. And for some reason there's a disconnect between seeing that with the well-being, you get productivity. And—yeah, so it's a—I think, you know, as more people develop Long COVID, unfortunately, it's just going to be necessary for employers to be more accommodating. So, it's kind of a—there's a benefit to all of this, if I can say it's a benefit. But right now we're looking at: 7.5% of all adults in the U.S. have Long COVID right now. That's a huge percentage of working people that will need these accommodations, or else, you know, we're going to have a significant portion of our workforce missing. So yeah, I think getting through that radical rest is important, should be part of people's day to day work schedule, if they need it. It's just going to be really crucial for our economy to stay afloat for people to, you know, continue to take care of themselves financially, take care of their families. It's just understanding that concept and understanding its *benefit* is going to be really, really critical.

AD: Can you think of anything else on a structural level that might help meet those needs? It seems like enhanced and increased flexibility and accommodations would be *highly* beneficial. Is there anything else that we could add to that list?

LM: Umm—

AD: I mean, I know a lot of people mentioned paid time off.

LM: Yes.

³³ A capitalist society refers to a society in which the free market and rights of private property are the foundation for any trade or development in that society. ("Capitalist Society: Definition & Roles of the State." Study. <https://study.com/academy/lesson/capitalist-society-definition-role-of-the-state-quiz.html>. Accessed 8 September 2022.)

AD: You know—A larger—

LM: Yeah—absolutely paid time off.

AD: —healthcare safety net. Which—What is your—?

LM: Yeah. Paid time off is critical, even for develop early—not developing Long COVID. Too many people are being pushed back into work—

AD: Mm. Mm-hmm.

LM: —after getting COVID.

AD: Mm-hmm.

LM: You know, not getting the adequate rest that they need, and those very crucial early stages.

AD: Mm-hmm.

LM: We've seen that people who were able to rest those first two weeks, because they had paid time off, are less likely to develop Long COVID. So that's a *huge* issue. Is the fact that we don't have universal paid time off, and even if you do have paid time off, it's usually inadequate.

AD: Mm-hmm. Mm-hmm.

LM: Yeah. So, those are—that ability to take time off at the beginning of the illness, but even throughout, you know, not being at risk of losing your job if you need to take a month off to really focus on that resting, and you know, trying to recover, and then doing a phased return, where you figure out what accommodations work best for you.

AD: Yeah, interesting, I like that: phased return.

LM: And that's, I think that, you know, those types of things are really important. Obviously, things like Medicare³⁴ for all, and you know, equal access to health care—

³⁴ Medicare is a program that the U.S. government funds to help individuals 65 or older afford healthcare by lowering costs and offering various payment plans. ("Medicare Guide." Investopedia. <https://www.investopedia.com/terms/m/medicare.asp>. Accessed 8 September 2022.)

AD: Mm-hmm.

LM: —is critical. And something that we're seeing—you know, it's severe lack of—not just, you know, people not having access to health insurance. But even when you *do* have access to health insurance, there's not enough providers focusing on Long COVID, who are well trained and educated in post-viral illness. Like the best specialists have a yearlong waiting list, and that's just, you know, not acceptable when—

AD: Mm-hmm.

LM: —But it makes sense when there are so many millions of people needing care all at once.

AD: Right. Yeah: big bottleneck. [long pause] Is there anything I didn't-- as we're wrapping up-- is there anything I didn't get to that you wanted to make sure that we talked about, or that we mentioned.

LM: I think—I mean I kind of mentioned this a little bit, but—I think, with all of the wins and progress that we've made as people with Long COVID, in a very short amount of time. You know, we have—as much as we still need—in the last two years, we have made significant progress. None of it would have been possible without all of the activists that came before us.

AD: Mm.

LM: And that includes, you know, *particularly* post-viral illness activists. But, you know, even before that and during that, HIV/AIDS³⁵ activism. And, you know, all of the wins that we've received over the last several decades in feminism, and in, you know, all of the various intersectional identities that people with Long COVID have. It's, you know, that's all been critical to getting us to this stage. There's so much work left to be done.

AD: Mm-hmm.

³⁵ Human immunodeficiency virus, also known as HIV, is a virus that makes the body attack cells that are responsible for fighting off infection. When HIV is untreated, it can lead to AIDS, or acquired immunodeficiency syndrome. There is no cure for HIV, but there is treatment that can help control it. ("What are HIV and AIDS?" HIV.gov. <https://www.hiv.gov/hiv-basics/overview/about-hiv-and-aids/what-are-hiv-and-aids>. Accessed 8 September 2022.)

LM: But, you know, I think it'd be naive to say that—and inappropriate to say that—you know, that Long COVID patient advocates did all this on our own.

AD: Mm.

LM: You know, there's absolutely no way that we did. We got this opportunity, because of how big of a scale this problem is. But also, because people paved the way before us that gave us access to these rooms and gave us access to, you know, this type of—being able to do this type of work.

AD: That's really moving and powerful, and I'm glad that—It seems like a good note to end on to come full circle. We started talking about what brought us here, and in some ways we've identified what brought us here, collectively. So, I think that's a really nice way to end. It has been such a pleasure to talk to you and an honor to interview you, and I'm grateful that you were willing to share your story and we're glad to have it as part of the Global Feminisms Project. So thanks again.

LM: Thank you so much, I've appreciated being part of this.

AD: Of course.