In This for the Long Haul: Ethics, COVID-19, and Rehabilitation

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As bioethicists and clinicians contemplate moving out of coronavirus disease 2019 (COVID-19) public health crisis mode and back to more typical standards of care, it is important to remember that the reverberating effects of COVID-19 include not only the societal impact of devastating loss of life, the amplification of systemic inequalities, and the moral distress of clinicians working in overwhelmed systems. They also include the ethical issues raised by the clinical impact of long-term COVID. Rehabilitation professionals are experts in addressing disabling conditions and focusing on quality of life, and are well poised to address the nuances and complexities of post-acute functioning. What are the ethical issues that are arising? In a previous PM&R ethics feature, we explored vulnerability, interdependence, and trust in the context of the COVID-19 pandemic. In this feature, we focus specifically on “long-COVID” and consider the stigma, uncertainty, access to services, and the doctor-patient relationship.

The long-term clinical impact of COVID-19 is revealing itself in homes and clinics around the world and the medical community is searching for answers. The terms long-COVID and long haulers was first coined by people with COVID-19 as they sought a name for their symptoms and experiences. They found their voice and community on social media. They shared stories, ways to cope, signs and symptoms, and how to advocate for services. Journalists and media attention heightened awareness. One widely read article by Ed Yong in The Atlantic magazine noted, “The physical toll of Long COVID almost always comes with an equally debilitating comorbidity of disbelief.” The Body Politic COVID-19 Support Group, which is often quoted in media stories, has started a Patient-Led Research Group, which has shared its findings with the National Institutes of Health (NIH) and plans follow-up surveys. Clinics specializing in this new disease have emerged and are charting the medical path to understanding the diversity and complexity of the symptoms and experiences.

Some of these long haulers are health care providers, who likely contracted COVID-19 on the job and balance professional responsibilities with symptom management and stigma.

This set of lingering symptoms has also been called post-acute COVID. In an August 2020 article published in the British Medical Journal about management in primary care, the authors describe post-acute COVID as extending beyond 3 weeks from the onset of symptoms, and chronic COVID-19 as extending beyond 12 weeks. In addition, they suggest that due to the lack of testing and the occurrence of false-negative tests, a positive COVID test is not a prerequisite for diagnosis. Some long haulers were hospitalized, whereas others recovered in the community. Some have access to ongoing health care and others lack access. Some have high health literacy and can be effective self-advocates; others are marginalized. As with any other clinical condition, each of these factors has ethical implications for patients, clinicians, and society.

I invited three contributors to consider the ethical issues related to long-COVID and sent them the following writing prompt:

“In some ways ‘long haulers’ or people with long-term sequelae of COVID-19 are like other rehabilitation patients, but given the context of the novel coronavirus pandemic, with all of the attendant unknowns, various ethical issues are emerging. Please share your perspectives on topics such as access, stigma, miscommunication, uncertainty, and prognostication. In considering this specific group of ‘new’ patients that are emerging around the world, we may learn new lessons, and/or more
deeply understand known aspects of the ethical issues in rehabilitation medicine.”

Our first contributor, Monica Verduzco-Gutierrez, MD, is a Professor and Chair of Rehabilitation Medicine working at the Joe R. & Teresa Lozano Long School of Medicine at UT Health San Antonio. She draws on her practice, having created an outpatient COVID recovery clinic, and underscores the clinical complexities of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and the ethical issues she has seen emerge in her practice. Our second contributor, Leslie Rydberg, MD, is an attending physiatrist at the Shirley Ryan AbilityLab, Monika and Henry Betts Medical Student Education Chair, and Assistant Professor of PM&R at Northwestern University Feinberg School of Medicine. She will speak from her perspective of caring for patients on an in-patient COVID recovery unit. She also brings forth the voices of her multidisciplinary team who were all experiencing this disease together for the first time. The third contributor, Melba Nicholson Sullivan, PhD is a licensed clinical-community psychologist; People, Culture, and Systems Consultant; and Chief Executive Officer/Founder of Freedom Flow Solutions, LLC. She will speak as someone who has trained and coached clinicians, and she herself had COVID. She describes her experiences and calls on all of us as health care professionals to rise to our ethical expectations. As always, I welcome ideas for the PM&R ethics/legal feature and can be contacted at dem9199@med.cornell.edu.

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Post-Acute COVID-19 Recovery Clinic and Ethical Considerations for the “long haul”

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“No one believes me. I feel COVID is eating up my brain.” I hear these words pierce my heart across the computer screen in my COVID Recovery clinic. I can no longer grab a hand. I cannot pass a tissue. I lean toward the camera and listen more intently. They are the survivors of COVID-19. From these fighters, I have listened and learned. As a physiatrist, it has not been difficult to adapt to caring for this patient population. I remind myself that our field came from rehabilitating persons surviving war and enduring the effects of polio. We are the essential experts of conditions impacting function and causing disability. We are specialists who adapt to many settings, from the intensive care unit to the football sideline. And through my experiences running a COVID-19 recovery clinic, I have seen several ethical issues that are unraveling in our field and with the health care system. These ethical issues—related to stigma, access to care, and health care inequities—will be further discussed within the population of “long haulers.”

Stigma

There is a large clinical spectrum of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection, from asymptomatic to severe multi-organ failure and death. A heterogeneous initial presentation, timeline, and treatment regimen based on severity and hospitalization adds to the varied outcomes. With more than 78 million people around the world who have now survived, we are finding that many of them have developed post-acute COVID-19. Early studies are showing that up to one in 20 people develop “long-COVID” and continue to experience symptoms weeks to months after the onset of the infection. For those who developed COVID-19 and were never hospitalized, I hear stories about how they lived in fear, alone in their bedrooms, further isolated from family, and shunned from physician offices for fear of them spreading the virus. Fevers, cough, aches, anosmia, and fatigue were among the initial symptoms. They lived and came out of their rooms. But certain survivors continued to suffer. Unsure how long these patients were contagious, physicians or other specialists continued to keep them out of the office. Unfortunately, most post-acute COVID-19 symptoms are difficult to quantify. The overwhelming fatigue, dyspnea, headache, body aches, inability to exercise, brain fog, and insomnia that continue for weeks to months are not apparent on an ECG. You cannot see the inability to walk to their mailbox on their chest x-ray or their echocardiogram. When a patient experiences brain fog and forgetting words, a brain MRI
can still yield a normal report. Their sleepless nights and headaches can only be described. Often, the patient with long-COVID feels that the symptoms are taking over their life and no one understands or wants to listen. There is still so much misunderstanding that we use quotes to describe the survivors or “long haulers.”

The fatigue, and the stigma associated with it, is what long haulers struggle with the most. It is comparable to the cancer population prior to the development of robust physiatry-led cancer rehabilitation programs. Years ago, when a woman had breast cancer and curative treatment, no one understood why she continued with ongoing fatigue. She was “cured” and there was less focus on the post-acute rehabilitation aspects. We now recognize and have developed guidelines and a subspecialty focused on this, as we should continue to do for long-COVID.

Access to Care

Prior to the pandemic there was already difficulty accessing adequate mental health services, which is further exacerbated during this public health crisis. Neurological symptoms and psychological illnesses have increasingly surged in post-acute COVID-19. Neural injury through inflammation associated with COVID-19, and its relationship with psychological symptoms has now been described in the literature. The pandemic and its related consequences, including quarantining and physical distancing, is also taking a toll on global mental health. Persons recovering from COVID-19 seem to be at greater risk of posttraumatic stress disorder, anxiety, and depression, and these comorbid mood disorders can worsen symptoms if not treated. In addition, there are issues with respect to access to psychological services, especially if it is not covered by a patient’s insurance.

Patients also have issues related to access to care due to the misinformation on transmission of the disease. The Centers for Disease Control and Prevention has created transmission-based precaution guidelines for patients with confirmed SARS-CoV-2 infection. Despite the symptom-based strategy that allows discontinuation of precautions after 10 days for non-hospitalized patients, many with post-COVID syndrome were denied access to clinic visits. In addition, patients have had difficulty getting to physicians due to dramatic backlogs. I have now also seen patients needing a post-acute brain injury rehabilitation program, but “Neuro COVID” is not a covered benefit on their managed care plan as it is a new disease state. Or these programs are not covered by some governmental payors such as Medicaid. A long hauler may have cognitive impairment, headache, and dizziness, and most definitely would benefit from this type of multidisciplinary program. More severe patients with acute cerebrovascular diseases, critical illness polyneuropathy and myopathy, and encephalopathy can get acute in-patient rehabilitation, but this is not an option for someone who was not hospitalized.

Healthcare Inequities

We have seen that COVID-19 is not an isolated disease. Contributors to COVID-19 outcomes are unequivocally multifactorial and are interlocked into many social determinants of health. Cumulative evidence suggests that certain factors beyond health care—such as socioeconomic status, neighborhood and physical environment, racism, and social context—play a large role in this new health epidemic. COVID-19 is disproportionately impacting minoritized groups in the United States. We are seeing an increased number of cases, hospitalizations, and death in American Indian, African American, and Hispanic persons when compared to White, non-Hispanic persons. There is also a disproportionate effect on those who are already underinsured. On top of high rates of unemployment during the pandemic, a person with COVID-19 may lose their job and, in both cases, insurance coverage. Without insurance, there is no option for a rehabilitation program.

Vulnerable populations—given their higher rates of infection and more severe disease—will have more morbidity related to long-COVID symptoms. As discussed by a Call to Action paper by Odonkor and colleagues, it is our duty as Physiatrists to provide post-acute care to all patient populations, especially those who are already overburdened by the global pandemic. There is a major risk of widening inequalities in outcomes in COVID-19 due to the disproportionate effect it has on certain minoritized communities.

Unsurprisingly, at the beginning of the pandemic the focus was on managing and prioritizing patients at high risk of death and with severe COVID disease in the hospital setting. Furthermore, most of the research and treatment options are related to acute COVID. There will be a need for longitudinal observational studies and clinical trials to better understand the consequences of COVID-19 in the population of survivors.

When the virus reaches global equilibrium, we will continue to see the impact on survivors of COVID-19. It is time to ensure we have adequate understanding, empathy, research, and medical coverage to help those with post-acute COVID-19. It is time to listen to all of those who say, “I don’t have my life back.”

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Recovery Unknown: Rehabilitation During a Pandemic

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In March of 2020, as the coronavirus disease 2019 (COVID-19) pandemic spread throughout the country, the uncertainty about the virus contributed to the general sense of fear and unease. In April, my stand-alone rehabilitation hospital opened up a COVID recovery unit. Our entire rehabilitation team (the nurses, therapists, social workers, physicians, pharmacists, housekeeping, and psychologists) was ready to hit the ground running to address the residual functional effects in our COVID survivors. However, we had no idea what to expect. How had these patients survived? What would they look like medically? What would their rehabilitation needs be? Could we accommodate their needs? Could we get these patients back home—back into their communities? It is one thing to survive the infection, but what happens next?

Now many months into this pandemic, our unit has served over 150 patients with COVID pneumonia or patients requiring rehabilitation who had asymptomatic COVID infections. Looking at a subset of the patients who have undergone rehabilitation at our facility, the average length of stay at an acute care hospital was approximately 26 days. Then they spent on average another 20 days participating in in-patient rehabilitation prior to discharge. We now know that rehabilitation plays a vital role in improving the COVID-related impairments our patients are experiencing. Rehabilitation works!

Access to rehabilitation services depends on many things including geography, insurance, provider buy in to the benefit of rehabilitation, and available rehabilitation resources during a pandemic. Unfortunately, not all patients have access to appropriate rehabilitation and this may lead to additional health care-related disparities.

In discussions with our multidisciplinary rehabilitation team, some key points emerged. Different team members shared their impressions of the social, emotional, and ethical issues that their patients faced. I share their perspectives below to give a fuller picture of the range of issues identified by the team.

Discharge Planning

We strive to get COVID survivors back home, back into their communities, back to work, and back to their regular activities. The road is long. We know that the recovery process is not over when the patients leave the hospital. The patients leaving in-patient rehabilitation felt the same relief and excitement upon returning home that most of our patients participating in rehabilitation with neurologic or trauma diagnoses experience. Emily Sanders, an occupational therapist working in the COVID recovery unit, said that her patients are “feeling lucky to be alive, excited about the progress they have made, and that they can’t wait to be at home with family.”

One of the most striking things rehabilitation professionals have seen is the fear of returning home and infecting family and loved ones. Talia Shapiro, a physical therapist working in the COVID recovery unit, said that her patients experience “fear and anxiety of re-entering the ‘real world’, getting re-infected or having this happen to them again, also infecting family members.” Those who are discharged home and continued to test positive for the virus were terrified of giving the infection to loved ones. One of my patients perseverated on returning home to his longtime partner, saying, “All I want to do is see my Sweetie. But I can’t get her sick!”

This unknown led to a huge increase in anxiety surrounding discharge planning. Kate Webler, a speech therapist working in the COVID recovery unit, noted that “many of the patients with whom I work express fear of the unknown-meaning, there are so many unknowns about this virus. The patients do not know if the impact will be permanent, the length of recovery time, or if they will ever resume life as it was pre-COVID. Returning to the community has its own set of challenges that can provoke anxiety. In the beginning of the pandemic, a patient with COVID was seemingly branded by society, leaving the patient feeling isolated. Now patients do not seem to have that social anxiety as the pandemic continues to spread; however, as new information is being published regularly, the patients report confusion about their ongoing risk of transmitting the virus or getting sick again.”

Abby Mitchell, a licensed clinical social worker who coordinates patients’ discharges from the COVID recovery unit, said that, “patients were afraid to have someone come in their home (eg, home health); families members were afraid to discharge patients home if they continued to have positive tests (even if they had already had the virus for months at that point); patients were very afraid to leave their home to go to the store/
doctor/outpatient rehabilitation, etc. due to fear of re-infection.” Sarah Berger-Clark, a licensed clinical social worker working in patient-family support, found that the patients struggled the most with the anxiety related to the uncertainty and the unknown that this virus brings. “Finding strategies to expand and accept their resilience has been the biggest success in treating the emotional limitations,” she said.

Clinical Uncertainties

In addition to the ethical issues regarding the uncertainties of returning to the community, we also faced uncertainties in the medical knowledge of how to treat people with COVID-related diagnoses. As rehabilitation professionals, we have treated many patients with residual functional impairments after prolonged intensive care unit (ICU) stays or severe infections, and we realize the severe toll that this can take on many different organ systems and the prolonged nature of the recovery process. Early on, many people in the general community were surprised to find that there were so many non-pulmonary ramifications of the infection. Our patients certainly experienced the expected dyspnea, generalized debility, and hypoxia. In addition, we saw high rates of dysphagia, cognitive dysfunction, stage III-IV pressure ulcers, renal failure, deep vein thrombosis, psychological impacts including anxiety and post-traumatic stress, and significant weight loss. In addition, there were several neurologic complications seen in this patient population, including strokes related to hypercoagulability, critical illness weakness, and pressure nerve injuries related to prone positioning. Many of these symptoms and clinical findings can be addressed by the rehabilitation team, but the potential for recovery is unclear. Many patients are still experiencing dyspnea, cognitive impairments, and fatigue months later. How can we as rehabilitation professionals counsel our patients on the expected recovery when we do not yet have the answers?

The good news is that patients do seem to be showing significant improvements when undergoing intensive rehabilitation programs. Ninety percent of the patients in our COVID recovery unit were able to discharge directly home; the other 10% required ongoing therapy at a nursing facility or were transferred back to an acute care hospital. As speech therapist Webler said, “We were the lucky clinicians that had the chance to see our patients on the upswing. While many of the post COVID patients discharging from acute inpatient rehab continued rehabilitation whether in day rehab or outpatient, most often they demonstrated capacity for progress and improvement.”

As a physiatrist, I continue to learn about the long-term consequences of COVID and how we as rehabilitation professionals can aid in our patients’ recovery. I remain committed to finding ways to collaborate and create solutions for responding to this novel coronavirus, and to work to ensure access for all patients to receive the inpatient and outpatient rehabilitation services they need.

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Rising to Our Ethical Expectations

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“When under duress, we do not rise to our expectations, but fall to our training level.”

Bruce Lee

When under stress, the health care system has constrained capacity to rise to its ethical expectations of nonmalefice, do no harm; justice, systemic access to appropriate services; fidelity, nurturing trustworthy relationships between providers and patients; and beneficence, promoting the well-being/quality of life for patients. Headline after headline reminds us that we are navigating overwhelmed systems. In this context, providers “fall to our training level,” the implicit and explicit medical model of a hierarchical expert relational stance and a supply-and-demand free-market approach to providing medication, which makes adequate health care a privilege not a birthright.

Since I returned home to New York City (NYC) from a Paris business trip on 1 March 2020, I have been seeking medical care to support my breathing. Coronavirus disease 2019 (COVID-19) was not recognized in NYC at that time, and I did not receive a formal diagnosis of lesions on my lungs “consistent with a mild case of COVID-19” until September 2020. I am a Black woman, licensed clinical-community psychologist, who has had titles such as Clinical Director of a New York State Office of Mental Health Clinic, Director of Community Outreach, and Clinical Assistant Professor of Psychiatry. These professional identities resourced me to navigate the lasting impact of COVID, but did not protect me from a stressed
U.S. health care system infested with structural racism and classism. A system out of alignment with its commitment to beneficence, justice, nonmaleficence, and fidelity.

Medical Gaslighting

My 6-month journey to getting an accurate diagnosis, like many COVID patients, was characterized by medical gaslighting. For example, in May 2020 I arrived at the emergency room of a teaching hospital with left chest and arm pain, as well as intense fatigue that I had been experiencing intermittently since March 2020. The travel nurse told me she’d been seeing people like me for a while but did not know if the doctors were acknowledging 8-week residual COVID symptoms yet. After several hours and tests, including a negative COVID test, the attending told me, “it’s allergies,” and dismissed the likelihood of COVID outright. Although she may not have intended it, I felt gaslighted. Gaslighting occurs in hierarchical, power-laden relationships. The systemically overvalued person intentionally and unintentionally denies, dismisses, and minimizes the undervalued person’s reality. Gaslighting can have the impact of leaving the systemically undervalued person traversing surreal feelings of craziness. It contributes to and exacerbates mental health symptoms such as depressed mood and anxiety. Notably, women, and possibly other systemically undervalued identities, are more likely to experience medical gaslighting. As providers we are trained to be experts in a hierarchical system, which makes it uncomfortable and difficult to sit with not knowing and facilitate collaborative relationships with patients. Although there are understandable reasons that providers may engage in medical gaslighting, gaslighting erodes a person’s trust in their own wisdom as well as their sense of emotional and psychological safety in the relationship, in this case with a provider. These dynamics undermine learning, cause harm, and constrain the development of an equitable, just system for all people. Medical gaslighting compromises patient well-being.

Collaborative Continuing Education

A collaborative approach is possible. I connected with a pulmonologist who took my symptoms seriously and acknowledged, “We’re all learning.” He called me doctor. He embraced my COVID diagnosis, rehabilitation journey, and goals as a continuing education opportunity. The qualitative data of my lived experience are as valued as current peer-reviewed articles, epidemiological statistics, and collegial consultations. He shares his hypothesis-driven approach, describing how the coronavirus may have intersected with previous illnesses like chicken pox/shingles and scarlet fever, to create the perfect storm of symptoms I continue to experience. We’ve developed a relationship oriented around mutual curiosity, vulnerability, and a desire to promote my capacity to breathe, tickle my child, walk daily with my partner, show up for my clients. To that end, my doctor also supported me in responding to the exorbitant priced $500 ($125 with insurance) monthly inhaler. First, he gave me a coupon. Then, he was available by email and responsive to my inquiries about other options that were more ethical and accessible. “My staff will look into it,” he wrote when the pharmaceutical company discontinued the coupon and the insurance company alerted us to a gap in coverage of the inhaler. Eventually he gave us samples to cover the gap. My previous experience as medical school faculty training physicians to work with torture survivors/asylum seekers made communicating with my doctor easy. Many patients would have given up and either gone without their medicine or gone into debt to support their capacity to breathe. Given my doctor’s current and probably increasing workload, it would have been easy for him to respond slowly or not at all. Notably, in the midst of COVID and an opioid crisis, my inhaler is upwards of $125 while my prn pain medications are $1.52.

Inequities

Most City of New York employees have the same insurance as I have. That means the people most vulnerable to COVID and most likely to deal with ongoing symptoms—Black, Indigenous, People of Color, subway conductors and bus drivers, crossing guards, educators, and first responders—have insurance that, according to my physiatrist, “barely covers the ink it takes to write the prescription.”

Mine was a “mild” case of COVID eventually diagnosed by my pulmonologist with magnetic resonance imaging. My physiatrist honors my interest in contemplative practice and the Gokhale Method, a posture and movement approach to restoring structural alignment and relieving physical pain through which I have experienced sustainable relief. I have the resources of collaborative professional relationships, community, time, audacity, and the personal and professional heritage to ask questions, push pause, and invite exploration of another way.

Yet, many people dealing with the long-term consequences of COVID are not as well-resourced as I am. They may be under- or uninsured. They may have learned to accept the authority of pharmacists, insurance companies, and medical providers without question. They may distrust their lived experience rather than see and name the gaslighting of others and a flawed system. A recent study of the consequences of COVID revealed both an increased incidence of mental health diagnoses such as anxiety, depression, and post-traumatic stress among COVID patients, and increased vulnerability to COVID for people who were already managing psychiatric diagnoses. Shared symptoms of common mood disorders include intense sadness and grief, fear, sleep disturbance, lethargy, and irritability. Evidence of how COVID affects the brain is still
emerging, and these are common sequelae to concussion and mild traumatic brain injury as well. These symptoms undermine people’s capacity to get out of bed, stay present, focus, wear a mask, stand 6 feet apart, and wait. The ethical chasms require patients to make extra phone calls, send emails, and persistently engage with the known justice and equity issues that systematically compromise access to mental and physical health care.

Questions for Reflection

As I reflect on my experiences navigating the health care and pharmaceutical marathon, I invite the reader to engage two questions with which I aim to encourage dialogue, collaboration, and creativity.

1. How am I using my privilege to co-create a safe, just provider-patient relationship that promotes physical and mental well-being?

2. What do sustainable prescription drug, insurance, and mental health care systems that expand all people’s capacity to heal look like? How will we know when we have shaped them?

COVID-19 is fertilizer. It has called forth pain and discomfort and amplified inequity. It illuminates the ways in which our current systems decenter an individual’s own knowing of their physical bodies. At the same time, it presents an opportunity to grow, to shift, and to evolve. No two COVID-19 patients present in the same way long-term because coronavirus modifies itself to the unique nature of the system it encounters. Therefore, the ethical rehabilitation journey requires remembering how to work collaboratively, be curious, and be driven by learning and transparent communication. It also requires holding pharmaceutical and insurance stakeholders accountable for the impact of their pricing and policies, while finding alternative pathways. Ultimately, it requires taking a stand for justice, beneficence, nonmaleficence, and fidelity.

Concluding Remarks

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These three pieces start an important conversation about rehabilitation ethics in the treatment of people experiencing long-COVID. Dr. Verduzco-Gutierrez shares her experiences from her outpatient COVID recovery clinic and underscores the complexity of the clinical phenomena and the role of stigma, access, and inequities. These are three key ethical topics that impact many people with disabilities, although the context of the pandemic has intensified the presentation. Dr. Rydberg reflects on her experiences caring for patients on an inpatient COVID recovery unit and adds to the discussion on clinical uncertainties with a focus on discharge planning. Discharge difficulties are common in inpatient rehabilitation, but this particular form of fear for loved ones, and fear of infection, are layered over already complex discharge planning. Finally, Dr. Sullivan speaks to us as a psychologist, Black woman, and COVID-19 survivor, who is still navigating the symptoms more than 6 months after onset. She reminds us to listen, collaborate, push for systemic changes, and continue to grow. All three pieces underscore the importance of humility and of using our skills to adapt and respond to known and unknown aspects of this pandemic.

As effective COVID-19 vaccines are on their way to many Americans, and as bioethicists move from considerations of crisis standards of care and pandemic responses to vaccine allocation guidelines, there remain the perennial ethical issues around justice, equity, minimizing harms, and maximizing benefit. I have been figuratively holding my breath for the COVID-19 pandemic to pass, for the constant worries, hypervigilance to infection control, scrolling through the alarming news and devastation, and for freedom to spend time with loved ones to become “normal” again. For many of our fellow citizens, the loss of loved ones has changed their lives forever. For others, the impact of the virus may continue to physically linger. We must be in it for the long haul and recognize, accompany, and collaborate to meet the challenges of the day.

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Disclosure

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Disclosures: Dr. Verduzco-Gutierrez has been a consultant for AbbVie/Allergan, Merz, Ipsen, and Medtronic, not related to this work.

Submitted for publication January 14, 2021; accepted January 14, 2021.