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Voices

Voices from a Pandemic

Our many voices form the human chorus. Here, we present six diverse perspectives that share a common thread: how COVID-19 has changed our lives. We hear about the difficulties of providing palliative care on the front, the challenges patients seeking gender-affirming surgeries face, the loss of rituals built into health-care visits, the pivots researchers take to study SARS-CoV-2, as well as the unique mental health impact of an ongoing trauma. These are but a few of the myriad voices that represent our COVID-19 collective. Yet they highlight a reality: a pandemic not only touches all people, but also elicits responses we never quite imagined.

Finding the Humanity in Telehealth



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Weeks into the COVID-19 stay-at-home order, I hit a milestone in my cancer journey: my first post-treatment follow-up. Unsurprisingly, it took place virtually. You might assume that as a Millennial (yes, I was one of those rare cases of breast cancer under 30), the transition to digital would have been easy—but I was just as prone to technical difficulties and the anxieties of remote surveillance. I have no doubt that as telehealth becomes standard, we will develop strategies for making things run more smoothly.

My biggest takeaway, however? To make telehealth work for patients, we have to think beyond the short amount of time spent on screen together. In-person appointments have rituals built into them: the drive to the office, sitting in the waiting room, a meal afterward. Now, an individual could easily log in and out only to find themselves left, in silence, to sit with their own thoughts. I've recommended to fellow patients that they schedule around their virtual visit, making plans to go for a walk or to have Zoom dinner with a caretaker. I believe that telehealth can, and will, change things for the better, but only if we keep in mind the full—and fundamentally human—arc of the patient experience, regardless of whether we're in an office or on a screen.

Palliative Care in a Pandemic



Richard E. Leiter, MD, MA
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Palliative care is ideally situated to help patients, families, and other clinicians through the COVID-19 pandemic. COVID-19 is a serious and often fatal illness that can lead to significant symptoms, particularly at the end of life. Patients and families are forced to make decisions that will have profound implications for the longevity and quality of their lives. Clear, empathetic communication; medical decision making; and complex symptom management are the hallmarks of our discipline. As COVID has torn through our cities, palliative care clinicians have worked to facilitate goal-concordant treatment decisions and, when necessary, to provide compassionate, evidence-based end-of-life care.

However, for palliative care clinicians on the frontlines, our practice has changed entirely. While we are accustomed to tolerating prognostic uncertainty in our decision-making, COVID's trajectories are less clear than those of cancer and heart failure. We've also been separated from the sights and sounds of our patients and their loved ones. We're either working virtually or not regularly going into patients' rooms to conserve personal protective equipment (PPE). Families are no longer at the bedside. As are all specialties, palliative care is adapting its clinical tools to COVID's shifting reality. More than ever, though, data will be essential to guide our response moving forward.

The Impact of COVID-19 on Those Seeking Gender-Affirmation Surgery



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Measures implemented to care for COVID-19 patients and to mitigate viral transmission have affected all patients. For those seeking gender-affirming surgery (GAS), the negative impact can be greatly magnified. Health care team members may unknowingly contribute to this with inadvertently stressful language. From a surgeon's perspective, scheduled surgery is "elective" (not "urgent" or "emergent"), an anxiety-provoking word that insurers use when declining coverage. Surgeries may appear in the medical record as "canceled"—an unfortunate misnomer. Providers should assure patients that surgeries are delayed, not canceled. Insurance is also a source of anxiety. Concerns that prior authorization might expire are compounded for those seeking GAS, given burdensome authorization requirements. Support documents from multiple providers might need to be resubmitted, which can be challenging due to delays in getting appointments, appointment cost, or providers no longer practicing in the area. Staff should proactively request authorization extensions. For genital GAS, potential stress relates to medically necessary hair removal. Service locations have been closed, and a delay in hair removal can further delay surgery. Health care team members have capacity to acknowledge and address stressors to improve patients' health and well-being. Other useful interventions include online video support groups and telehealth visits. Staying informed and sharing information about new online resources is another way that team members can offer support; see [Fenway Health](https://www.fenwayhealth.org) for examples.



Shifting Focus on SARS-CoV2



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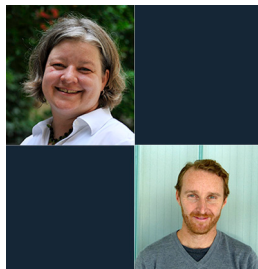
Creating innovative solutions for clinical needs is driving me as a translational scientist.

My lab develops patient-derived, cell-based assays to study the basic biology of cystic fibrosis transmembrane conductance regulator (CFTR) and discover drugs that enable personalized medicine for cystic fibrosis.

When the lockdown started, we stopped many long-term patient cultures ready for analysis, which halted multi-center clinical-stage drug development studies despite the opportunity to continue essential experiments. No experiment was more essential than prioritizing my team's health and stopping the spread of SARS-CoV2. We would use the lockdown to work from home, read literature, complete lab notebooks, and write reviews and grant proposals.

This all changed when Gimano Amatngalim, who develops airway culture models in my lab, triggered me the next day: "Jeff, we should do something with Corona." I realized that the essential experiments during lockdown should focus on SARS-CoV-2. We could exploit our airway culture models—in the past three months we screened 1500 drugs in 5 patient airway organoids—to study respiratory virus infections. What followed were exciting new collaborations and a rush to set up SARS-CoV-2 infections in our airway models that involved half of the lab staff. I find it highly exciting how the SARS-CoV-2 pandemic is bringing scientists together in exploring solutions for this urgent clinical need.

A Grassroots Response to COVID-19 by Canadian Scientists



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University of Toronto
Guillaume Bourque, PhD
McGill University

We met late on a Friday night via Twitter, at the end of a hectic week when most Canadian research labs shut down due to COVID-19. Guillaume, the bioinformatics director of the McGill University Genome Centre, had noticed that Canadian COVID-19 researchers were struggling to find collaborators and key resources. Tara, an infectious diseases researcher at the University of Toronto, had noticed that early national mobilization of scientists to work on COVID-19 diagnostics was central to the successful German and South Korean responses, but was not happening in Canada. We had independently begun building tools to help the Canadian scientific response to COVID-19 by collecting research resources and scientific volunteers. By the next day, courtesy of Twitter, we had met ~20 academic, government, and private web developers; science communicators; bioinformaticians; and graduate and medical students and formed COVID-19 Resources Canada. Our grassroots organization is now an ~4,500 volunteer network that facilitates coordination and scientific capacity-building for Canadian public health, research, and grassroots COVID-19 responses, together with CanCOVID, a Slack community for Canadian COVID-19 researchers. In epidemics, proactive, rapid response is crucial. We try to meet this need with the tools each of us has at hand.

Detecting and Treating Mental Health Consequences of the COVID-19 Pandemic



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The COVID-19 pandemic has created an urgent need for research efforts to understand its mental health impact and develop new treatment strategies for survivors, family members, and frontline healthcare workers. Many healthcare workers in highly affected areas are likely to develop symptoms of depression, anxiety, and trauma. In the short term, it will be essential to delineate the scope of COVID-related psychiatric syndromes, track their trajectories over time, and identify modifiable risk factors for informing interventions. In the long term, these studies could also present new opportunities to advance our understanding of the neurobiological mechanisms underlying stress-related psychiatric disorders and develop better treatments. It will be critical to characterize the neuropsychiatric manifestations of COVID-19 infection and determine whether they are driven directly by viral invasion of the brain or by systemic intermediaries. Stress-related mood and anxiety disorders are usually episodic conditions, waxing and waning over time, yet it is unclear how mood, anxiety, and trauma symptoms evolve and why some individuals are affected while others are spared. Indeed, the molecular and circuit-level mechanisms underlying the induction, maintenance, and recovery from stress-induced affective episodes are largely unknown. Answering these questions will be critical for optimizing existing treatments and designing novel interventions that are accessible, scalable, and tailored to at-risk populations.