

The Early Days The Postkidney Transplant Recipients' COVID-19 Journey

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The shock of a “new normal” is standard for kidney transplant recipients. Yet, coronavirus disease 2019 (COVID-19) is testing us in ways that we are only starting to understand—about this novel virus, others, and ourselves.

We offer context on the basis of our experiences. Our goal is to help the kidney community define this historic era for postkidney transplant recipients, without letting COVID-19 define us.

Glenda's Journey

February 29, 2020: “Circumstances suggest community spread” (1). The Centers for Disease Control and Prevention (CDC) and Kirkland, Washington, report the first US COVID-19 deaths.

I live in the adjacent city. The first casualties were patients on dialysis. Some lived in a long-term care facility near my local grocery store. The outbreak's proximity to me was palpable.

I immediately sounded the alarm at work and in the kidney transplant community: “Be wary of COVID-19!” I stopped nonessential travel and self-isolated with my husband. Because I am immune suppressed, he posted the stop sign (Figure 1) on the door to notify people not to enter. My son has not been inside my house for 130+ days. Everything is delivered and disinfected before anything is brought inside. As a kidney transplant recipient, myriad factors place me at high risk for infection. Many, like Patrick, have contracted COVID-19. So far, I have avoided the virus.

My perception of COVID-19 evolves as swiftly as the information avalanche expands. Is the safe distance now 13 feet (2)? Anxious people contact me for kidney transplant-specific references. Like them, the dearth of trusted information sources frustrates me. I propose two practical recommendations that would be beneficial: (1) a trusted information source would publish a brochure titled “For Kidney Transplant Recipients: How to Combat COVID-19” and (2) local transplant centers would contact their community of kidney transplant recipients to provide trusted resources and explanations of changing data. Everyone in the kidney community is learning and adapting. It is challenging because COVID-19 is novel and adapting too (3).

Living with kidney disease makes me an expert at adapting. COVID-19 is another variable. It requires adjustments to my existing regiment to maintain optimum kidney health. As COVID-19 cuts new paths into our lives, I will adapt—because worrying is not a strategy.

I have offered a broad perspective on how COVID-19 affected my thoughts on and approach to living with kidney disease post-transplant. Patrick's story is a case study of a COVID-19–positive, postkidney transplant experience.

Patrick's Journey

September 20, 2019: The date is etched in my memory as my last routine transplant center visit. Yet, my kidney journey has been anything but normal.

I received my transplant on April 21, 2017. While I woke up from the surgery, the kidney did not. The next 33 days in the hospital were hard. I had three major surgeries and many dialysis treatments. On day 47, my kidney started working. Since then, I have not had any major health incidents. That is, until I began my COVID-19 journey.

Several factors place me at high risk for contracting COVID-19. They include transplant-related immune suppression, diabetes, hypertension, and obesity. To protect my new kidney, I wear a mask on all public transportation. I adopted the best practices long before the CDC issued COVID-19 guidelines.

March 12–13, 2020: COVID-19 information for kidney transplant recipients was scarce. Just before I left, my transplant team approved my travel to a Washington, DC meeting. Riding the train back home, I got a call from them telling me to take precautionary measures and self-quarantine for 4 weeks.

March 14–15, 2020: On March 14, my pastor informed me that one of the church members tested positive for COVID-19. He encouraged me to contact the COVID-19 hotline and my transplant center to inform them of my possible exposure. My wife is my care partner. We both travel a lot for our jobs. We were feeling fine until this week. By March 15, we both had high fevers, coughs, runny noses, low energy, body aches, and chills.

I contacted my transplant center. They told me to self-quarantine and to call the COVID-19 hotline if

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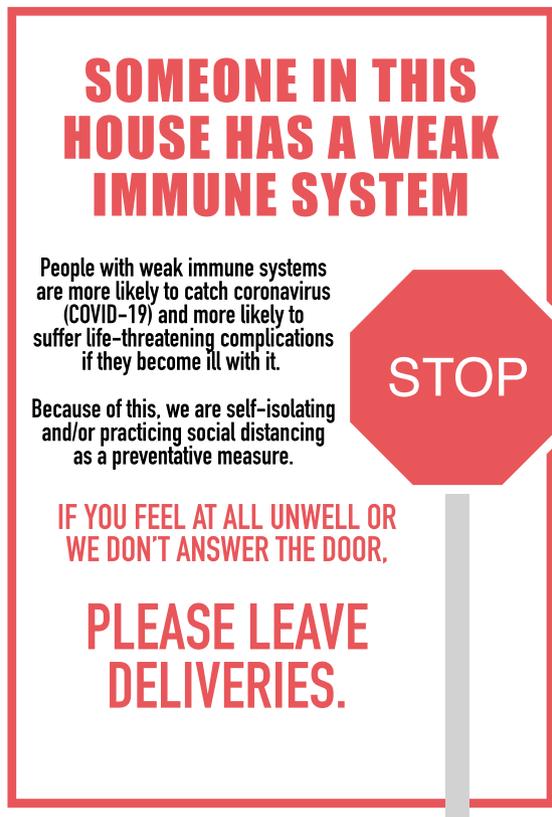


Figure 1. | A sign that can be used if your household includes someone with a weak immune system.

my symptoms worsen. Daily telehealth engagements replaced my scheduled doctor's appointment.

March 20, 2020: My symptoms were worsening. I contacted the hospital's COVID-19 hotline several times requesting a test. After the fourth attempt, I finally got tested. The administrator said to expect my results within 3–5 days.

March 23, 2020: After being turned away following an emergency room visit, the hospital finally admitted my wife. I alerted my transplant care team. As a precaution, they prescribed a 7-day regiment of hydroxychloroquine (Plaquenil) for me: 200 mg twice per day. Hydroxychloroquine was their "go-to" medicine for COVID-19–positive, postkidney transplant recipients.

March 30, 2020: After 10 days, my transplant care team delivered my COVID-19 test result. It was positive. Although my symptoms were subsiding, the body aches, chills, and low energy remained. Because I self-quarantined from March 13 and my hydroxychloroquine regimen was almost finished, they said I should be on the road to recovery. The COVID-19 convalescence period varies, but 8 weeks after my transplant team's prognosis, I am still recovering from the effects of COVID-19 (3).

April 11–16, 2020: New, unfamiliar symptoms surfaced: blurred vision, persistent nausea, appetite loss, weight loss, confusion, chest tightening, extreme coughs, numbness and tingling, fatigue, fast heart rate, dizziness, decreased urine stream, and irritability. They were not consistent with what I knew about COVID-19.

My transplant nephrologist consulted with an epidemiologist and infectious disease physician. We agreed I should check into the hospital overnight for outpatient testing. In addition to a second COVID-19 test, blood draws, and laboratory work, they performed an electrocardiogram, computed tomography scan, echocardiogram, and stress test.

The second COVID-19 test was negative. My laboratory work looked great. My heart test was unremarkable, but the doctors could not explain the recent symptoms. I believe these side effects are common for hydroxychloroquine (4).

Kidney transplant advocates nationwide agree that being high risk for the COVID-19 infection is scary. After sheltering-at-home, returning to work is scarier. Our safety depends on our colleagues' vigilance about hygiene and distancing.

Disclosures

P.O. Gee reports membership and leadership positions with American Association of Kidney Patients, Board of Directors; American Society of Nephrology Diabetic Kidney Disease-Collaborative Task Force; Center for Dialysis Innovation, Patient Advisory Board and Human Factors Working Group; Chronic Disease Coalition Southeast Region Co-Chair; iAdvocate, Inc., founder and Chief Executive Office; Kidney Health Initiative Patient Family Partnership Council; Otsuka Pharmaceutical, Advisory Board Member for their autosomal dominant polycystic kidney disease campaign; Patient Family Centered-Care Partners Advisory Board; Quality Insight ESKD Network 5 Medical Review, Board of Directors; and Quality Insights ESKD Network 5 Patient Advisory Committee Chair. He also reports receiving honoraria from APOLLO APOL1 Long-term Kidney Transplantation Outcomes Consortium; CareDX Patient Panels Guest Speaker; Center for Disease Innovation PAB and Human Factors Working Group; Community Advisory Council, representing the Cleveland Clinic; Otsuka Pharmaceutical Advisory Board; and Patient Family Advisors Network Guest Speaker. G.V. Roberts holds memberships or positions with American Association of Kidney Patients, ambassador; American Association of Kidney Patients, speakers bureau; American Society of Nephrology COVID-19 Response Team; American Society of Nephrology COVID-19 Response Team, Transplant Subcommittee; Can-SOLVE CKD International Research Advisory Committee; Center for Dialysis Innovation Patient Advisory Board; Home Dialyzers United, advisory committee; International Nephrology Society, Global Trials Focus-Accessible to Patients; Kidney Health Initiative Patient Family Partnership Council; Kidney Precision Medicine Project: Community Engagement Committee, Collaboration Committee, Return of Results Committee; Kidney Precision Medicine Project, Director of Communications; Kidney Research Institute Patient Advisory Committee; and OUI Works, founder and Chief Executive Officer. She also reports receiving honoraria and financial support from American Society of Nephrology, Kidney Week speaker: "The Role of the Kidney and SGLT2 in Glucose Homeostasis and Kidney Disease" Workshop sponsored by the National Kidney Foundation; APOL1 Delphi Consensus Meeting funded by AstraZeneca; APOL1 Long-term Kidney Transplantation Outcomes Consortium; Center for Disease Innovation, Ambulatory Kidney To Improve Vitality (AKTIV) Human Factors Project, funded by Veterans Administration; Center for Disease Innovation, Director-External Relations and Patient Engagement; Community Advisory Council funded by the National Institute of Diabetes and Digestive and Kidney Diseases; International Nephrology Society, Research

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