

Living Behind the Mask Amid Two Pandemics: COVID-19 & Social Injustice

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COVID-19 has put a spotlight on what the kidney community has known for decades. Underlying diseases such as diabetes, hypertension, and cardiovascular disease, leaves individuals, especially people of color, vulnerable to severe medical conditions. As a COVID-19 survivor and a post-kidney transplant recipient, I fall into the category of these underlying diseases. When you incorporate my chronic illness with the current climate of fear, anxiety, and sadness due to the uncertainties with COVID-19, it negatively impacts your mental and physical health.

I can recall in late March 2020, COVID-19 infected my wife, Tina, and I. Tina's symptoms had worsened to the point that the physicians admitted Tina into the COVID-designated ICU for six days. During that time, our only means of communication was through FaceTime. Gazing at her and seeing the streams of tears running down her face left me helpless and devastated. As a husband unable to physically be near the woman who never left my side during my tumultuous kidney transplant journey, all I could do in return is to show my support and optimism through words of encouragement. During our interactions, my words were masking the pain, hurt, and hopelessness of our situation.

There was a point during a FaceTime conversation where I was looking at my wife lying in her hospital bed, struggling to breathe. For a brief moment, I had a flashback to my April 2017 kidney journey. On April 21, 2017, I received a kidney transplant. When I woke up from the surgery, the doctor told me that my new kidney was not working yet. During my transplant journey, I endured twenty-four hours of hemodialysis every other day, a total of four surgeries, thirty-three days hospitalized and ending with my kidney starting to work on the forty-seventh day. During my journey, Tina refused to leave my side. If it were not for her loving comfort and reassurance, I do not believe that I would have survived that journey. Now that the table has turned, I cannot do for my wife as she had done for me.

So, amid our battle with COVID-19, I view the disproportional numbers of Black, Hispanic/Latino, indigenous, and Asian Americans impacted by this novel virus. I remember that it took four separate attempts to get a COVID-19 test because I was not "sick" enough. I would explain that I am in the "at-risk" group due to my immunocompromised system because I am a kidney transplant recipient. The COVID Hotline at my hospital would not budge. I had all the symptoms that the CDC had published, yet the hospital would not administer a COVID-19 test until my symptoms worsened.

Finally, On March 20, 2020, I get tested for COVID-19. There are so many thoughts going through my head as I am waiting for the nurse to administer the COVID-19 test:

- Why did it take so long for me to get tested?
- I live with CKD, Diabetes, hypertension, and Obesity, yet I am not sick enough; why?
- Did I not sound "sick" enough, and how sick is sick enough??
- Am I going to lose my kidney?

Eventually, I had to calm myself down and respect the process. The doctor informed me that I would receive my results in approximately three days. Three days realistically turned into ten days. During my wait-time, the doctors admitted Tina to the hospital for pneumonia and COVID-19. Due to her testing positive, I contacted my transplant center and informed them of Tina's positive test result. During our telephone discussion, I have prescribed a medication called Hydroxychloroquine to "get ahead of the virus," as my physician told me. Considering how politicized this medication was, the doctor explained

that this was the go-to medication at that time for people living with a kidney transplant. I valued my transplant care team's opinion over my apprehension, and at this point, I was too ill to be cynical about not taking this medication. I agreed to take medicine.

On March 30, 2020, I get my test results, and I tested positive for COVID-19. I was not surprised by the results. Tina was discharged from the hospital the day before I received my test results. We were physically distancing within our house, wearing our face mask, hand washing regularly, and being overly cautious. In my mind, I figured if I take my medication as required, I will be fine. The week of April 11-16, 2020, I experienced some strange symptoms that I had not experienced previously. I had heart palpitations, chest pains, headaches, nausea, confusion, brain fog, inability to concentrate, and moderate-to-severe fatigue.

As I found myself trying to maneuver through these new symptoms, I am still concerned about my wife's recovery; trying to fulfill my ministerial duties in offering prayer and counseling to those who are ill and grieving, and trying to limit my intake of social and news media because of all the harmful content. On April 17, 2020, my Nephrologist admitted me to the hospital after consulting my transplant care team on my newer symptoms. While in the hospital, the doctors administered a battery of tests to ensure that I had good kidney and heart functions. After a day and a half, my Nephrologist informed me that I experienced the prescribed medication's side effects. My organ functions were normal, and the nurse administered another COVID-19 test, which my results came back negative. I would need to allow the side effects to run its course because this virus is still new, and different symptoms from the exposure of COVID are still in the investigative and research stage.

Within the confounds of recovering from this dreadful virus and now being diagnosed with Post-Infection Fatigue Syndrome, I am still trying to understand what normalcy means to me. I am trying to understand the social injustices that continue to plague this country, especially in healthcare. For many, COVID-19 has exposed the lack of access, equity, equality, diversity, and inclusion within the healthcare system. When reading Biblical scripture, I always refer to Matthew 22:37-39, "You shall love the Lord your God with all your heart, with all your soul, with all your mind. This is the greatest and most important command. The second is like it: Love your neighbor as yourself." The question that I ponder in these troubling days is, "Do we know how to love our neighbors for who they are as we deal with two pandemics?"

As an Ordained Minister who was in a broken state of being, I did not have the luxury of resting and healing correctly. My phone always rang; text messages kept coming in, and email overflowed with prayer requests. I could barely pray for my wife and myself, much less someone else, but I knew I had to forge ahead. There was one distressful moment that will haunt me for the rest of my life. A good friend and fellow kidney warrior were in hospice during the pandemic. He reached out to me and asked me to pray for him and his family, so I accommodated the request. This young man had been in divorce proceedings while fighting for his life. One day I received a call from my friend asking me to call his father because he did not know how much longer he would be around. I immediately called his parents and gave them this news. His parents lived approximately two hours away-from the hospital, where he was staying. As his parents were near their son's location, their path was interrupted due to a social injustice protest. While the parents were waiting for a clear path to the hospital, I was on the phone praying for his comfort, healing, and restoration. At that very moment, his wife informed me that he had died as I was praying for him. He did not die of a kidney complication; he died of a broken heart.

As a person living with kidney disease, at times, I felt minimized by COVID-19. I felt left out of the conversation when it comes to a viable treatment option. When I put on my face mask to enter the world of COVID-19, those who see me only see a Black American man wearing a face mask to protect himself from possible infection of this invisible virus. They fail to see a Black American man living with fear, anxiety, sadness, depression, and concern with losing my kidney function and my life due to an invisible virus and social injustice. I do an excellent job of concealing my feelings behind my invisible mask. Yet, during this storm, I have learned things that will remain with me for the rest of my life.

Someone once told me that I was the "Poster Child for CKD and COVID-19." At first, I took it as an insult, but I now wear it as a badge of honor after some considerable thought. During this season of COVID-19, I lost many friends and peers to this virus, yet I survived. I realized that I did not have time to feel sorry for myself or worry about someone's nickname for me when kidney patients are dying of this dreaded virus. No matter the storm of COVID-19 or the storm of social injustice, I must use my lived experiences in both storms to navigate the ship and honor those fallen kidney warriors' legacy. These two pandemics should have caused my demise, but they gave me the strength to become bolder in work within the kidney community. If COVID-19 and Social Injustice were persons, I would share the following Biblical scripture from the Book of Genesis, Chapter 50, verse 20a so eloquently surmises... "As for you, you meant evil against me, but God meant it for good to bring about this recent outcome."

As a post-kidney transplant recipient and COVID-19 survivor, I will embrace my new role in being the Voice of the Voiceless and the Face of the Faceless in the fight for equitable and equal health care, treatments, and clinical trials for CKD and COVID-19.

Disclosures: P. Gee reports Honoraria: Otsuka Pharmaceutical Advisory Board, Center for Disease Innovation Patient Advisory Board/Kidney Research Institute Patient Advisory Committee, Patient Family Advisors Network, APOLLO APOL1 Long-term Kidney Transplantation Outcomes Consortium Community Advisory Council (CAC), CareDX, Bayer International, Vertex International. Scientific Advisor or Membership: ESRD Network 5 MRB; AAKP BOD; APOLLO Steering Committee's Community Advisory Council; Otsuka Pharmaceuticals Advisory Board, and University of Washington Center for Dialysis Innovation (CDI) Patient Advisory Board and the Human Factors Working Group Member and PFCCpartners Advisory Board. Other Interests/Relationships: AAKP Ambassador; AKF Ambassador and Kidney Health Coach; NKF KAC; UNOS Ambassador; PCORI Ambassador; NCC PFE-LAN SME; KHI PFPC Member; KPAC Member; Quality Insights Renal Network 5 PAC Chair; ASN Diabetic Kidney Disease-Collaborative Task Force, PFA Network Advisors Diversity, Equity, and Inclusion Workgroup.

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