Vaccinated but Not Protected—Living Immunocompromised During the Pandemic

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My B cells love extracurricular activities. They are dedicated overachievers, passionate about their jobs. That's how I think of them when I'm in a magnanimous mood, which makes me feel a little guilty for slaughtering them with rituximab. But I do so since the autoantibodies they churn out make me so sick—and the relative absence of my B cells was a fact I didn't dwell on too much—until the COVID-19 pandemic hit in force.

When I'm not seeing patients in the emergency department, I help train college students to go door-to-door to register people for the coronavirus vaccines, part of a racial justice project to increase vaccine coverage in the hardest-hit neighborhoods in the Bay Area. Often I divide them into small groups to role-play conversations with community members. The effectiveness of the vaccines is one of the facts that undecided people find most persuasive; I’ve taught the students.

They practice again and again, and I’m proud of them: They’re getting skilled at delivering the key messages. “These vaccines are so much better than the flu shot,” they say. “They’re almost entirely effective at preventing hospitalization and death.”

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What they say holds true for most people—but not for me. After the arrival of SARS-CoV-2 vaccines, my friends are now hiking in Hawaii and whitewater rafting in the Grand Canyon. They are slurping ramen at a Japanese restaurant or sipping mojitos at a Peruvian one. They date people on Tinder without a second thought and gather for birthday parties.

For me, it feels like the pandemic might never end. I knew vaccination might not work for me. Because rituximab destroys the ability to produce antibodies, it blunts responses to other vaccines too. I’m fortunate to have colleagues who study T cells, and they measured my T-cell responses after vaccination against SARS-CoV-2. They drew my spike protein antibodies too. And my T-cell responses after vaccination against SARS-CoV-2. They drew my spike protein antibodies too. And my T-cell responses after vaccination against SARS-CoV-2 were...totally lackluster. Both the level of antibodies I generated and my T-cell responses were far too weak to offer any assurance of protection.

The day after learning that news, I had to get rituximab again. In the infusion center, I lay back in the recliner in my sweatpants and slippers, blasted music through my head-phones, and stared up at the bag of monoclonal antibodies, the fluid inside entirely clear, innocuous in appearance. Yet I knew that every drop into my IV line was further decimating not only my miscreant B cells but also my freedom. Rituximab would grant me a different freedom—freedom from the neuropathic pain that blow torched my feet or the fatigue that sent me straight to bed after a busy shift. But weighing the 2 options—the risk of COVID-19 intermittently tailing me vs a disease that might debilitate me again, I wasn’t sure which was worse.

A few months into the pandemic, one of my mentors told me that the situation reminded her of the early days of HIV. “All the language is about risk,” she said, “with all the stigma of whether certain people are risky.” She hated the situation, which only exacerbated divisions of class and race and housing status and imposed physical and emotional restrictions on people that many couldn’t uphold. I agreed: We needed more empathy for the teen who couldn’t bear any longer not to board a plane to visit his dad. These days I know that I should feel the same about the vaccines since the reasons people don’t get them are complicated and contextual. I recognize that I should approach with acceptance the fact that many will choose to forgo the shots, but I can’t seem to make myself feel what I believe. The cognitive dissonance unnerves me.

Instead of mustering equanimity and compassion, I often feel that the pandemic has tossed me into 3-legged races with strangers, headed toward a finish line of normalcy I can only reach if they get there too—and that a lot of them decide after a few strides that they’d rather go to a bar. My reaction shames me because I know from interactions with my own patients that for many, the barriers to vaccination are structural. They fear that registering for a shot will endanger their immigration status, worry about asking for a day off work, lack access to reliable information about the vaccines in their primary languages, or understandably mistrust the health care system in the setting of institutional racism. But other people ascribe to a very American conception of freedom—one evident in everything from policies around gun ownership to labor laws. Freedom, some believe, entails the freedom to harm others. John Stuart Mill would clobber them.

I scan The New York Times over coffee every morning. “Reaching ‘Herd Immunity’ Is Unlikely in the U.S., Experts Now Believe,” reads one headline. I keep drinking my coffee pretending that I find this okay, interesting even—just like I fixate on the fact that my lack of a vaccine response is academically fascinating, in order to tamp down how personally devastating it is.
“Vaccinated Americans May Go Without Masks in Most Places, Federal Officials Say,” the front page announces. I know that the unvaccinated will happily ditch their masks along with the vaccinated, that a trip to the supermarket will only become more dangerous for me than before. As their freedom expands, mine will shrink.

“Tossing their masks, jumping on side-by-side treadmills, sharing peanuts next to fellow sports fans, the vaccinated find special freedoms await,” comments another article. Society is being partitioned in 2. I want so badly to leap the wall.

I've turned down the job I wanted at the city tuberculosis clinic. I shouldn't work in a tiny room jammed with coughing families. I tell Doctors Without Borders that no, I can't deploy now, even though I've worked overseas for years. In these decisions, I realize how much of my identity has centered around my career. Lack of response to the vaccine makes the edges of my self feel moth-eaten.

One Tuesday, grand rounds is entitled "COVID-19 and immunosuppressed patients." I watch the footage and at the end of the session, the chair of the department of medicine says, "It really does feel like March or April 2020 but now with a very specific patient population." He's right. There's so much about myself I can't know at present, an uncertainty I breathe every day.

In the comments section beneath the video when it's posted online, someone writes this:

The idea that symptomatic immunosuppressed patients aren't clearing the virus and can be hosts for developing variants is rather terrifying. If those patients are out in the community without awareness of their status, they are absolutely vectors of infection.

Between the uncertainty and the stigma, I think of patients who became infected with HIV in the early 1990s and survived. My situation doesn't even begin to compare to theirs in gravity. I'm not suffering from a virus that was, at the time, uniformly deadly; I'm not suffering from any virus at all right now. But I do have a new inkling of how they may have felt, with a deeper understanding of what my mentor was conveying in her observations about how people get tarnished as risky. It never occurred to me that someone might write about me as a potential "vector," not as a human being.

If the virus becomes endemic, as it likely will, I can't live the way I do now forever, with my ambitions collapsing in upon me at the age of 37. I want to work in South Africa again, hear live music, and laugh with friends at the Burmese restaurant we all love. The way I've practiced harm reduction with patients, I'll have to practice it with myself. It's tough when scientific knowledge is so nascent and I take a drug that elevates the risk of severe COVID-19. It's hard to conceive of the fact that if COVID-19 never abates, the guy next to me in the movie theater could transmit a virus that might kill me in a few weeks. I don't know how I'll handle this. I know so little about my future these days—and like many physicians, who tend to sketch out their plans a couple years in advance, it makes me uneasy. For the moment, it's a discomfort I have no choice but to accept.

I sit down with a steno pad to sort out my thoughts. Can I have dinner indoors with friends? Yeah, probably, if they're all vaccinated. Can I hop on a plane for a sorely needed vacation? Likely not yet. Concerts? No. Corner store without a mask? No. Visit to my grandmother? Yes. I need to see her. But it will be tricky with my cousin's little kids, whom I adore, staying there too.

I write this list and resolve to have as full a life as I can within constraints most of my friends no longer face. Then I drive to work for a 12-hour overnight shift. The other physicians in the emergency department mostly wear surgical masks now. Exiting the car, I put on my N95 knowing I won't be able to take it off until morning.

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