



## The art of medicine

### More than medical mistrust

I turned off the ignition and sat still. Up until that moment, I'd been excited about this day. But now that it was here, I felt this strange mixture of angst and ambivalence. A sudden urge welled up in me to grab my phone, call the centre, and cancel. I told myself, "You don't have to do this." I reassured myself, "I know."

I stepped out of the parking garage and made my way towards the building. Once I reached the ramp leading to the entrance, I froze. My feet felt glued to the asphalt and a few tears slid down my cheeks. Why was I crying? I pressed the heels of my palms into my eyes and took a big drag of air. It was exactly 2 minutes past the start time of my appointment. I told myself, "You really don't have to do this." I reassured myself, "I know."

My phone buzzed and startled me. It was the vaccine trial coordinator reaching out to see if I would still be coming. I paused before answering. "Yes. I'm walking in now." They were pleasant when I stepped inside. Even behind the mask, I could see from the twinkle in their eyes that they were smiling. They took my temperature, asked a few questions about my health status, and then escorted me to an elevator that, for safety reasons, I'd ride up alone. My inner voice began speaking again. "You can still leave, you know." And I told myself, "I know."

My hands were wringing in my lap. The coordinator sat directly across from me with a clipboard and began the process of informed consent. I felt my pulse quickening. Each breath I took behind my mask pushed plumes of condensation onto my glasses. I removed them, wiped them off, and pinched the nose on my face cover before placing them back on my face. The coordinator asked, "Is everything okay?" "Yes," I replied. "I just need to be able to see." They nodded and continued the process. With every statement on that long list, I listened intently. I asked them to repeat or reword the parts that weren't clear to me or that I perceived as unnecessarily complex. My responses were slow and measured. Then, after the final question, they handed me a stack of papers with stickies on the areas for me to sign, telling me to ask if I had more questions.

That's when it happened. Without warning, a cacophony of sounds clattered inside of my head. Throaty voices cried out in protest. There was the tinkling of metal instruments punctuated by shrieks of pain and conciliatory murmurs. Then came scuffling sounds along with the clink of handcuffs. Someone wept in rhythmic tics and then, just for a few moments, there was silence. Next, there was the sound of a brass band playing. Then came the laughter. Soft at first, but quickly becoming louder, blended with applause and sounds of celebration. I closed my eyes and took in a deep breath, hoping I could drown it all out. I could not.

The coordinator spoke my name and shook me from my inner thoughts. They offered a smile and asked how I was. I said, "Um, sorry, yes, I'm fine." The coordinator checked again, "Do you have any questions?"

I sifted through my brain for more, hoping to cover not only my own queries but all of those important things that those before me had not been afforded the chance to explore. I asked and asked and asked until I ran out of questions and breath. I wish it felt like enough. It did not.

I am a 50-year-old Black American woman physician who is a descendant of slaves. My parents are from Alabama and, in the 1940s, my maternal grandparents were students at the Tuskegee Institute, now Tuskegee University. All four of their children, including my mother, were born and raised in Macon County, AL—in the very hospital that conducted the now infamous Tuskegee Study of Untreated Syphilis in the Negro Male. And on this day, I initiated my participation in a phase 3 clinical trial for a vaccine against severe acute respiratory syndrome coronavirus 2.

The narrative of Tuskegee being synonymous with that horrific study came as a surprise to me. As a fourth-generation graduate of Tuskegee University, I'd always associated the word Tuskegee with Black excellence, uplift, and family connection. Just hearing those three syllables would bring to mind the sprawling campus with dormitories named for slavery abolitionists like Frederick Douglass and filled with majestic brick buildings built by students post Reconstruction. Although I'd heard about the syphilis study from my parents growing up, it wasn't until I entered residency at a predominantly white



The grounds and buildings of Tuskegee University

academic institution that I'd learn of how the medical community and beyond had rewritten the name of my alma mater as synonymous with Black people and medical mistrust in the USA. "Tuskegee" would be the explanation given when a Black person declined a medication, a vaccine, or enrolment in a clinical trial. It was both hurtful and infuriating. Perhaps it was because, as a student at historically Black institutions like Tuskegee University and Meharry Medical College, I'd learned about the medical atrocities and experimentation that long preceded and followed the untreated syphilis study. Additionally, I didn't like the way the awful and unethical study seemed to microinvalidate the extraordinary legacy of Tuskegee University to such a large number of people. Moreover, such reference to the Tuskegee study and medical mistrust oversimplifies something far more complicated.

There are trust issues when it comes to African Americans and the US health-care system. There is also a justified fear that our human lives might be dispensable in exchange for scientific discovery benefiting those with privilege and who are white. The historical basis for this, which began long before the untreated syphilis study in Macon County, underscores a larger, ongoing issue—the value of Black lives. In the Antebellum period, it was the millions tortured through chattel slavery as property. Post Reconstruction, there was state-sanctioned convict leasing followed by Jim Crow laws and domestic terrorism. The uncovering of the disturbing events in the Tuskegee study was no more than another chapter over centuries in US history. It is a story that continues with the deaths of unarmed Black Americans, mass incarceration, the achievement gap, and the astounding health disparities seen every day and now amplified by COVID-19. All of it is intertwined.

For Black Americans, the fellowship derived from our shared suffering has always been a place of connection and, out of necessity, support. Just as our ancestors clung to each other in the bowels of slave ships, risked their lives for freedom, and collectively put themselves in harm's way for civil rights, this solidarity has saved our lives for generations. As a result, this allegiance to all who came before us remains. The emotional turmoil I felt when signing that enrolment form wasn't as simple as medical mistrust. It felt like disloyalty.

Conversely, I work in health care as an academic physician at a safety net hospital. I have seen health disparities with my own eyes and have been on the receiving end of desperate phone calls from Black patients, family, and friends. Like many, I've read the research, lamented the paucity of Black enrollees in clinical trials, and wrestled with the applicability of the results to my predominantly minority patient population. Then COVID-19 came crashing in. As the pandemic disproportionately impacted Black, Latinx, and Indigenous people, the urgency to find solutions that might benefit us rose. With every hospital

admission, personal text message, and Centers for Disease Control and Prevention report, it became more evident than ever that alongside a strong public health and epidemiological response and wide-ranging strategies to mitigate and address health disparities, a vaccine would be crucial. And therein lies my internal tug of war as a Black physician. While I know that a historical reluctance to assist scientific discovery is warranted, I also recognise the importance of research that can potentially save lives.

Prospects of COVID-19 vaccines becoming available look promising. But early surveys suggest that some people from historically disenfranchised and marginalised groups might feel hesitant. Some of it could be mistrust and fear—but we should also consider the rightful anger against the establishment that dehumanised Black people over and over again. Also, beyond resigning every minority to groupthink, recognition is needed that informed consent and refusal are individual choices—and rights.

Acknowledging every aspect of the multigenerational barriers for Black Americans to enrolment in clinical trials is critical to moving forward. We are not simply untrusting—we remember. And there is still far too much evidence of Black lives not mattering in our society. This evolution of trust will call for more than scientists with excellent communication skills. We need a seismic shift in our relationships with Black lives as demonstrated through government and societal actions, policies, investments, and outcomes. Medical mistrust is just the tip of a 400-year-old iceberg that has to be chipped away from every direction.

When I rolled up the sleeve on my non-dominant arm, I squeezed my eyes shut and braced myself. A syringe with either a new COVID-19 vaccine or placebo would soon plunge into my muscle. I didn't hear any sounds but even behind closed eyelids and foggy glasses, I could see. This time it was faces I saw—some crying, some protesting, others unsuspecting and trusting. Some were lifeless, splashed with shovelled dirt from unmarked graves or worse, unearthed and taken for dissection in medical schools. But then came the smiling faces waving at me from clinic waiting rooms. The security officer giving me a fist bump through my car window at Grady Memorial Hospital, my sons lost in hugs with my ageing parents, and the exuberant alumni crowd dancing with the marching band at a Tuskegee University homecoming game. As the scent of the alcohol swab wafted into my nose and the needle drew closer, I told myself a final time, "You don't have to do this."

And because I know that I don't, I did. It is as much my right to consent as it is to refuse. On this day, I said yes.

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**Further reading**

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