The ‘truth’ about ALS: Reconciling bias, motives, and etiological gaps

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By

In February of 2019, I was giving a talk in New Haven, Connecticut. My paper was an overview of my research, titled “Is It a ‘White Disease’? ALS, Race, and Suffering in St. Louis, MO.” I closed with an ethnographic vignette from a key informant, Tyrell, whose brother had died from amyotrophic lateral sclerosis (ALS) three years prior, after being diagnosed only six months before his death.

I described to the audience how Tyrell shocked me after our first interview by giving me a hug and whispering, “Thank you for encouraging me to do this [interview]. I feel so much better. I’ve been bottling this up for too damn long.” I explained that Tyrell had been silently suffering from the trauma of seeing his brother be released from prison, get diagnosed with ALS, and die from the disease, all within twelve months. At the time, I argued that ALS researchers refused to consider that Black patients are afflicted with ALS, and part of my ethnographic work was to uncover the validity of this assertion.

After the session, I was approached by Casey, a Black woman from Atlantic City who was a doctoral student at a prestigious university in Washington D.C. She asked if we could talk, and after I agreed she looked over to me and said, “I think my boyfriend has ALS.” Stunned, I then listened to her 45-minute story about her year-long attempt to help her boyfriend, Dewayne, find answers for why his body had been deteriorating over the past three years.

With tears in her eyes, Casey described his frequent falls and the times she went to his home and found him in a pool of urine and feces. She described the way his muscles had atrophied, leaving Dwayne too weak to pick up a fork, let alone make his own meals. Casey described multiple visits to medical centers at Georgetown and Howard, and countless visits to community neurologists and primary care physicians that left them more confused about Dewayne’s condition. Referencing an anecdote I shared about a Black journalist’s delayed ALS diagnosis after doctors assumed he was a drug user and/or HIV sufferer, Casey expressed anger and frustration that the doctors they had seen assumed the same of Dewayne. She explained that his Medicaid insurance only functioned in Washington,

D.C., which complicated access to care for a second opinion. But Dewayne was “in the streets” making decent money—so, he tried to assure the hospitals he could pay for his visits in cash. Nonetheless, multiple research hospitals refused to see him. She looked at me dejectedly and sighed, “Chelsey, what do I do?”

Casey and I worked together to get Dewayne the answers he deserved. I connected her with various non-profit organizations to get her durable medical equipment, social support, and, most importantly, a doctor’s visit at a leading ALS clinic in Maryland. Unfortunately, they had to wait four months for the appointment.

After much prodding by Casey, Dewayne finally agreed to meet with me during my visit to the D.C. area. As I walked into an upscale casual dining restaurant in Bowie, Maryland, there stood Dewayne wearing an Avenger’s t-shirt, Nike sweats, and Jordan sneakers. Next to Dewayne stood a light-skinned Black man with an ankh around his neck and all-black attire. Dewayne introduced him as his bodyguard. A tired-looking and makeup-less Casey approached me and gave me a warm hug. As soon as we sat down, Dewayne looked at me and said, “So, you’re the one that’s been helping me out?” I smiled shyly and said, “No, I’ve just been giving Casey some advice.” He said, “Nah. You’ve been doing more than that. Thank you.”

He hesitated for a moment and then asked, “So, what’s the tell-tale sign for this ALS shit?” I wasn’t ready for this line of questioning. Frankly, I’m not used to being asked questions. In my head, I was prepared to field some softball questions to Dewayne about his diagnosis journey and ongoing physical changes— hoping to expand my ethnographic research from St. Louis to new geographic sites.

I quickly gathered my thoughts and said, “Well, the diagnosis means that a person would have both upper and lower motor neurons affected.” He looked bewildered. “So basically, my upper and lower body?” he asked. I nodded. At this point, he began to open up more about his experiences, recounting how three years earlier he had been diagnosed with a hairline fracture in his ankle that never resolved, despite doctors’ assurances that it would. In his subsequent visits, doctors were unable to provide any answers that moved him toward a permanent recovery. As he continued sharing his story, I observed Dewayne struggling to eat his lunch. When Casey quietly whispered across the table, “Do you want me to cut your food?” he quickly retorted indignantly, “Nah, I’m good.”

He was not “good.” Dewayne was having issues with gripping the fork and raising it to his mouth, and he left most of his food uneaten. Towards the end of our lunch, he looked over to me and said, “I know I don’t have

ALS. I know God wouldn't do me like that. I'm only 36, and I'm a Black man. I read online that this doesn't affect black people like that." I was speechless for a moment but then managed to but respond: "I hope you don't have it either." My intuition told me otherwise.

That day I wrote in my notes: "I'm not a doctor. But you can tell that he has classic signs of ALS, and has had it since 2016, and no one has formally diagnosed him and that breaks my heart." A month later, the day of his appointment, I received a text from Casey that said, "It's ALS. The Hopkins doctor thinks its [sic] ALS too. He's COMPLETELY in denial and gets offended if anyone mentions that it's ALS." Despite my hope for this 36-year-old Black man, he was formally diagnosed with an incurable disease over three years after his first symptoms.

How did this happen? Why did it take three years for Dewayne to be diagnosed with ALS? The easy answer to these questions is that the U.S. healthcare system is broken and abysmal. However, this is much deeper than a broken healthcare system. This is more than negligence, more than poor physician training, and more than a Black patient's purported distrust of the medical system: this was bias. This is bias. Over the past twenty-four months of ethnographic "homework" (Carter 2019), I have learned how epistemological biases in scientific research, coupled with biases in public awareness systems, lead to inadequate consideration of who can or cannot contract certain diseases. Gendered and racial biases in the ALS community are written off as further "unknowns" of the disease pathology and etiology rather than opportunities for scientific exploration.

In an embodied way, as I saw with Dewayne and others, ALS researchers and clinicians are biased toward the belief that Black people cannot contract certain diseases, like ALS. Doctors did not initially diagnose Dewayne and instead decided that he *must* have HIV, multiple sclerosis, an immune disorder, neuropathy, or be a drug user. Dewayne did not have any of these ailments. The ALS disease experiences of White people are consistently foregrounded in public imaginations of ALS, and diagnostic biases based on race and gender negatively impact the lived experiences of Black people with ALS—leaving their experiences out of the story completely and perpetuating a biological narrative that ALS only affects white people. Consequently, Black ALS patients are not a part of knowledge production about how ALS impacts their lives biologically, socially, and culturally.

The Black patients I observed have longer diagnostic time periods than white patients and more negative experiences with doctors and resource partners. Anthropologists, sociologists, public health scholars and historians of medicine have long confirmed that Black bodies are "made" and experienced differently than white bodies by Western biomedicine,

which is committed to racialized notions of immunity, susceptibility and death (Benjamin 2019; Davis 2019, Hoberman 2012, Roberts 1999, Wailoo 2014, Williams & Mohammed 2013).

Using Margaret Lock's "local biologies" (1993) as a point of departure, I argue for the need for the concept of racialized local biologies. A racialized local biology is an important analytic that frames the way race and medicine are enacted in the U.S. and globally; the concept of racialized local biologies forces attention to the biases in favor of whiteness and examines how diseases adapt in certain racialized communities. The "local" matters because race and racism as constituted in the U.S. are particular to the nation's specific context, which is apparent in hyper-segregated St. Louis, the site of my research.

For anthropologists and others to truly attend with the ways racism operates in the U.S. and globally, we must attend to the specifics of U.S.-based constructions of race and disease and the affective dimensions of race, racialization, and racism at home in the U.S. The local matters. My intervention situates "racism" in the foreground of analysis as a powerful force within medical systems in the production of kinds of bodies, moving beyond the invocation of "structural violence," "biopower," "social suffering," and other frameworks of socio-cultural marginalization within biomedicine and its knowledge production practices. The 2020 COVID-19 pandemic's impact on the Black community sheds light on the importance of examining "local" functions of racism and health (Carter & Sanford 2020).

When we anthropologists look at Black people and people of color broadly with ALS, or any rare, life-limiting disease, we have to realize how and why race, gender, class, and culture operate. These powerful social constructions are just as important for patient care as are biological and genetic discoveries of disease etiology and pathology. Inequitable healthcare encounters, especially those that disproportionately affect Black people with ALS, rupture stories of White-only disease experience.

Exposing these biases in ALS epistemic paradigms will push biomedical researchers to reimagine how race and class operate in niche diseases like ALS in the U.S. This reimagining disrupts assumptions that Black people are exclusively affected by "Black-only diseases," like diabetes, hypertension, sickle-cell and certain cancers, while White people only are susceptible to a myriad of unknown, life-limiting diseases worthy of research, innovation, treatment, and a cure. The particular localities of racism and bias are embedded in scientific inquiry and systems of care that overwhelmingly affect the poor and the marginalized. And frankly, Black people in the U.S. and across the diaspora deserve better.

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