

Sarah Alger:

Welcome to Proto, a podcast that explores the frontiers of medicine. And welcome to Diagnosis, a series about the past, present and future of a medical cornerstone. I'm Sarah Alger.

Dr. Altaf Saadi:

And I'm Dr. Altaf Saadi. In 1966, Dr. Martin Luther King Jr. said, "Of all the forms of inequality, injustice and health is the most shocking and the most inhuman because it often results in physical death."

Tragically, Dr. King's words ring true half a century later.

Sarah Alger:

Inequality in health care begins all too often at the moment of diagnosis. While the signs of disease should be objective, clinicians are human and they come to the bedside with a lifetime of preconceptions. Research increasingly shows that those preconceptions around gender and race can cloud clinical thinking, leading to a misdiagnosis or one that fails to accurately connect the dots.

Dr. Altaf Saadi:

The fields of psychology, psychiatry and neurology have particularly grappled with bias and diagnosis over the past decade. We are embarked on an effort to explain gaps in care, which have at times been dramatic. We're also reckoning with the way that some diagnoses have been used to perpetuate racist practices.

Sarah Alger:

Diagnosis through the Bias Filter, coming up on this episode of Diagnosis, brought to you by Massachusetts General Hospital.

As Dr. Eric Rosenberg noted in our first episode of the Diagnosis podcast, turning test results and medical histories into a diagnosis still relies on the human brain, and each clinician's brain comes with its own all-too-human presets. In recent decades, there has been a concerted effort to map where physicians may fall prey to unconscious bias. This is especially important for bias that involves perceptions of underserved groups, including women and racial minorities. Many studies have shown how bias can lead to subpar care for these groups. Female patients, for instance, have been shown to need more visits before they initially receive a diagnosis, perhaps because clinicians at first discount their worries. Black Americans, similarly, are more likely to have their accounts of pain dismissed, a lost signal that can lead to an important diagnosis being missed or delayed. Illness that affects the brain has especially drawn scrutiny. Race appears to affect the judgment of many clinicians. Stroke, epilepsy and Parkinson's disease are less well diagnosed among Black patients. Black children are less likely to get a diagnosis of ADHD than their white counterparts. And while Black Americans are almost twice as likely to develop Alzheimer's disease and other dementias, they are 35% less likely to be diagnosed with those conditions. There are also instances where concepts from neurology have been used as a weapon by those outside the profession. In the deaths of George Floyd, Daniel Prude and Elijah McClain, three Black men who were killed in police custody, a factor noted in each death was excited delirium, a diagnosis not listed in any major disease or syndrome manual.

Here to talk about bias in neurology is Dr. Altaf Saadi. Dr. Saadi is a neurologist at Massachusetts General Hospital and a principal investigator in the Neurodisparities and Health Justice Lab. Dr. Saadi is the co-author of a new article in the journal Neurology that provides a comprehensive review of race-based disparities in the field. Dr. Saadi, welcome to the Proto podcast.

Dr. Altaf Saadi:

Thank you so much for having me, Sarah.

Sarah Alger:

Let's start with this concept of excited delirium. What does that diagnosis mean and where did it come from?

Dr. Altaf Saadi:

Yeah, so excited delirium is a term that started being used in the 1980s. It was coined by a medical examiner, Dr. Charles Wetli, who is based in Miami. And he initially used it to explain deaths related to cocaine intoxication. And then later he extended the term to explain the deaths of 12 black women in Miami who were sex workers who had died with some cocaine in their system. And then later he turned out to be completely wrong because it turned out that those women had actually died at the hands of a serial killer. And normally this would render that term completely obsolete. But he was backed by at the time and paid by law enforcement agencies. And he sort of continued to push this theory. And he, you know, also said some pretty outrageous and racist things related to his theory that if they were to be repeated now, we would completely denounce and even ideas that have been completely debunked, like saying black people were more prone to this because of their genetics. And then a small group of researchers and consultants including him, again many who had connections with law enforcement and some to Taser International now called Axon, that's a U.S. company that produces technology, products and weapons, began to just keep advancing and pushing this diagnosis forward. Even to the point where Taser Axon, for example, was paying for copies of books related and pushing this diagnosis of excited delirium for all forensic pathologists at an annual meeting, for example. And what the diagnosis is now turned into is this catch-all diagnosis that captures a range of symptoms that include elevated heart rate, blood pressure, agitation, fever, and even symptoms that are rooted in racist tropes about Black men, like being impervious to pain or having superhuman strength.

And a lot of these symptoms in reality can come from a range of different diagnoses. So drug intoxications or withdrawals, or mental health illnesses like bipolar mania or psychosis, and, you know, all these different diagnoses would be treated differently. But this term ends up being a convenient cause of death for in police custody, as well as a reason to justify brutality instead of actually treating the underlying conditions of these symptoms that could come from a host of different legitimate diagnoses that I just mentioned.

Sarah Alger:

Can you tell us more about how that diagnosis was used in more recent cases, such as with George Floyd?

Dr. Altaf Saadi:

Yeah, so while Officer Chauvin was kneeling on George Floyd's neck, another officer said something about, Oh, I'm worried about excited delirium. And as I mentioned, one of the features of excited delirium is that, or again that's purported to be part of this diagnosis that is really scientifically meaningless. But the people who are advancing this diagnosis, one of the features that they say is that people can be impervious to pain or have superhuman strength, or can become suddenly agitated. And so it's used by law enforcement officers to justify superaggressive tactics like neck restraints and in George Floyd's murder a knee-to-neck restraint. But this is one of the aspects that to me really drives home what a problematic diagnosis this term is. Because on one hand it's used to explain the deaths that occur when people are in police custody. Even those studies have shown that in the overwhelming majority of those deaths, and we're talking about 90% of those deaths are occurring in the context of being restrained.

So it begs the question, was it the pseudoscientific diagnosis that's hiding behind medical language to look legitimate at the surface that's causing these deaths? Or is it actually these tactics by law enforcement officers that's causing these deaths?

Sarah Alger:

What can the neurology community do to address this?

Dr. Altaf Saadi:

So I want to speak to both the medical community at large as well as the neurology community. So this diagnosis has been refuted by several medical organizations, so including the American Medical Association, the American Psychiatric Association, the American Academy of Emergency Medicine. And I know there are some professional organizations that are actively working on position statements as we speak. I was a co-author of a report by Physicians for Human Rights, which is an international human rights organization that released a report on this topic and really took a deep dive into the history, the literature.

We did multidisciplinary interviews, interviews with affected families, and we found that the term is scientifically meaningless. And I think a big element is issuing statements that explicitly and emphatically denounce the use of this as a medical diagnosis and as a cause of death. And then pushing for our local state, federal governments to really steer away from using this and sort of lending our expertise to create evidence-based policies including in law enforcement. And another element of it is pushing the same local, state, federal governments to increase resources and social services to address mental health. And at the end of it all, it's really about getting medically trained professionals as primary responders and decision makers in acute medical emergencies instead of law enforcement. These are people coming in with real medical issues and we want them to be treated medically by medically trained professionals.

On the neurology front, I do want to acknowledge the American Academy of Neurology, which I'm a member of, which issued a position statement last year against the use of neck restraints in law enforcement. As neurologists we know that restricting the blood flow to the brain, even briefly, can cause permanent injury to the brain, including stroke, cognitive impairment and even death. So it was really great that the AAN did this and is an example of what professional organizations can do, again in terms of leveraging their clinical expertise to not just speak about medical issues that are happening in our clinic rooms but about medical issues that we see affecting and killing people in the community.

Sarah Alger:

I'd like to talk about a few things the medical community has a little more control over, focusing specifically on diagnosis. We mentioned some examples earlier where physicians may miss a neurological diagnosis because of racial bias, and this appears to happen in stroke, Parkinson's, Alzheimer's and epilepsy. What might be happening in these cases?

Dr. Altaf Saadi:

So traditionally I think the focus was on the individual patients, and certainly from their perspective, there are factors that influence diagnostic delays. So there could be different cultural perceptions or understanding of aging, or stigma related to diseases like epilepsy. But increasingly there's been recognition of structural and institutional factors that play a role and also physician or clinician factors that play a role. So just as some examples, at the institution level, for example, there are institutions that don't accept Medicaid or certain health insurances. So low-income individuals might have a really difficult time getting access to specialists to even make the diagnosis to begin with. There are geographic disparities that we know exist, in terms of urban versus rural areas, in terms of regional differences. So we're actually in Massachusetts where there's the largest density of neurologists in the U.S.

I think that all these different factors that influence who is even getting in the door in the clinic room to see a neurologist. And then in terms of physician factors, there are questions we need to ask, like, who is getting referrals to specialty care? So we did a study that found that Black and Hispanic patients were 35% to 40% less likely to see a neurologist. And when we accounted for primary care physician referrals,

it sort of reduced that, so showing that the referral patterns were playing a really big role. And so thinking about, well, who's getting referrals to see a specialist? And then once they do show up, what tests are being done? what's the assumptions that go into diagnostic testing to get the ultimate diagnosis?

So there's one study that showed that young Black men who were showing up to an emergency department with a stroke were more likely to get drug testing or urine toxicology screening than if you were white also showing up with a stroke, even though the rates of drug use are equivalent in those populations. And so what we see in that case is then you're introducing stigma, right? In the care of those young black men. And then in the case of the white people who were coming in with strokes and who were using drugs, you're missing out in potentially helping them, right? So I think it's really important, and I know this is sort of going off on a tangent in terms of your question, but I think it's really important to frame this as: When we don't prioritize equity and put it front and center, everyone loses. It's not just patients from marginalized backgrounds. Everyone loses out when you're not thinking about each patient holistically.

Sarah Alger:

You're the principal investigator for a project looking at people with limited English proficiency. And part of the study is looking at diagnostic testing. What kind of diagnostic missteps can happen there?

Dr. Altaf Saadi:

I became interested in this because this was something that I was seeing in my own clinical encounters starting in residency. So this was many years ago. But I was noticing that because it would be so difficult for clinicians to communicate with patients who didn't speak English as their primary language, or even to get an interpreter because, you know, you'd have to wait and it just adds time and it's inconvenient that clinicians would just end up getting extra testing that would be unnecessary, even costly for the patient, instead of taking those steps to optimize the communication. So as an example, assuming someone has a neurologic problem like dementia, and maybe that involves starting a workup, like getting an MRI of the brain, maybe even doing a lumbar puncture, but then getting an interpreter and finding that person is perfectly fine when you got an interpreter who was speaking their language, their dialect. And I can't begin to tell you how often I've seen that, where people end up getting unnecessary and costly tests. So I really wanted to see if this mapped out beyond my anecdotes and anecdotal experience. And so we're working on that using a nationally representative data set. And from the preliminary results, it does look like there is signal towards that but it is preliminary, but I look forward to sharing that in the future once we finalize our results.

Sarah Alger:

You've looked extensively at how immigrant communities meet and navigate the health care system. What factors affect the diagnoses they get?

Dr. Altaf Saadi:

So one of the things I like to emphasize, and I alluded to this in an earlier question, is: At the end of it, the root causes are really similar across disenfranchised communities. So, for example, the issue of bias is there, irrespective of which community, but it might play out differently. So in the context of immigrant patients, for example, there are assumptions associated with their education and language speaking ability. So oftentimes I see that patients whose primary language is not English are assumed to have lower educational background or have poor health literacy. And that may be the case in some cases, but it's not the case universally. And so I think it's important to think about a lot of the same social and structural factors as well as the biases that we've talked about and thinking about how those apply to immigrant communities. But at the end of it all, it's sort of similar issues that affect and are common across communities.

Sarah Alger:

In a recent paper, you describe how clinicians can promote anti-racism, not only in clinical practice, but also the research frontier and in policy. Could you walk us through how that happens?

Dr. Altaf Saadi:

Yes. So I'll begin with the research end. So on the research front, we know that non-white persons are underrepresented in research studies across conditions. So you can take any neurologic condition, really, even nonneurologic conditions, you know, MS, dementia, epilepsy, and we see that there is significant underrepresentation. And so there really needs to be a strong push to change that in the studies that we see, whether that's translational or clinical, and we need to shift our frame that this is not just something that's nice to have or a nice bonus, but it really is integral to good science. Good science is representative. And that's something we need to shift again, or how we think about these.

Another element from the research end is really thinking about and engaging, uh, community members in the research process. One of the methodologies that I like to practice and use in my own research is community-based participatory research. That's including community stakeholders, not just in, Hey, does the survey look good? or Can you recruit people for us from your center? But: Are we asking the right questions? Can you help us in interpreting this data? What stands out to you? So you're really thinking about and involving communities in the entire process of research. And I think that also yields better science.

And then the final two points I'll make about the, on the research front is: One, we really need to recruit and support investigators from marginalized backgrounds. We know that Black researchers, for example, are less likely to be awarded NIH R01 grants. And then two, we know that it's really challenging to fund studies that engage communities that might take a bit longer to do than other research because of that element of community engagement. So we really need to shift and align funding priorities with public health need and with community engagement. On the policy front, I think that can happen--the anti-racism that you asked about--can happen at a lot of levels. So at the policy level, and that can happen at various levels, right?

In terms of our professional organizations or local state government. I think about our annual meetings, for example, for our professional organizations, what's being talked about in symposium, right? What is being offered in terms of continuing medical education? Who are the people who are on editorial staff that review articles and maybe push authors when they see disparities being attributed to race as a biological construct, right? So those are the things that can happen at the organizational or professional level. And then beyond that, we can think about advocating for policy changes. You know, earlier we talked about the excited delirium, for example. There are also other policies like advocating to increase Medicaid reimbursement or reimbursing telephone visits, which we know low-income individuals are more likely to engage in. And I do a lot at the individual level in terms of writing op-eds or joining grassroots advocacy efforts. But I think there's also a really important element of that, that we need to think about, um, because we really should be leveraging our expertise to think about these issues.

Sarah Alger:

In 2020 STAT News named you a Wunderkind, "one of the next generation of scientific superstars." If you could make big changes on the topics we've discussed today, what would those changes look like?

Dr. Altaf Saadi:

That's a very big question, <laugh>, but I will do my best to answer that. I think about it in terms of attaching real incentives to promoting diversity across multiple levels. So for example, in the context of research that we just talked about, maybe adding a criterion for having a diverse team, right? Having it be as a bonus if you come in as a community-engaged project with community partners. So thinking

about those things being actively incentivized rather than just being, Oh, this is the icing on the cake. No, it really should be something that we integrate into how research is funded or thought as being worthy and valuable. At the organizational level you might think about financial incentives for leaders in when they achieve diversity recruitment or promotion metrics.

So I think that that large element of thinking and attaching real incentives to promoting these efforts. And then I will say something I think a lot about is the role of our health care institutions in promoting equity sort of beyond just lip service. I think about institutions that have raised minimum wage for people who work within their walls, who have invested money in local businesses, in housing, in food access. So really thinking about how we can uplift and improve the health of the community, rather than just seeing people as individuals coming into clinic rooms that we then treat.

Sarah Alger:

Terrific. Well, thank you so much, Dr. Saadi.

Dr. Altaf Saadi:

Thank you for having me. It was a really great conversation.

Sarah Alger:

And listeners, thank you for tuning in to the Proto podcast. Today's podcast was produced by Joshua Krisch, Bradley Klein, and Jason Anthony. Thanks also to our technical directors, Adam Keller and Nathan Marcus. Subscribe to the Proto podcast on iTunes and Stitcher, and follow us on Facebook, Twitter, and Instagram. Stay safe and see you next time.