

Three physicians discuss the history of experimentation and medical abuse



AMA MAKING THE ROUNDS

Making the Rounds

Three physicians discuss the history of experimentation and medical abuse and implications for today

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Featured topic and speakers

In this episode of Making the Rounds, AMA Medical Student Section member and co-chair to the Minority Issues Committee, Joshua Carrasco, leads a panel of physicians through discussion on the history of racism, experimentation and malpractice in medicine, as well as the long-term implications of these violations of the Hippocratic oath.

The physician panelists are Michael Knight, MD, MSPH, Luis Seija, MD, and John Paul Sánchez MD, MPH. Knowing this history will hopefully bring enlightenment provide valuable insight to better empathize, listen and advocate for patient concerns.

Speakers

- **Joshua Carrasco**, member, AMA Medical Student Section; co-chair, Minority Issues Committee
- **Michael Knight, MD, MSPH, FACP**, internal medicine and obesity medicine physician, George Washington University; chair and alternate delegate, AMA Minority Affairs Section Governing Council
- **Luis Seija, MD**, internal medicine and pediatrics; delegate, AMA Minority Affairs Section
- **John Paul Sánchez, MD, MPH**, executive associate vice chancellor, HSC Office for Diversity Equity and Inclusion

Host

- **Todd Unger**, chief experience officer, American Medical Association

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Transcript

Unger: In this episode of Making the Rounds, Joshua Carrasco, AMA Medical Student Section member and co-chair to the Minority Issues Committee leads a panel of three physician leaders brought together to discuss the history of racism, experimentation and malpractice in medicine, as well as the long-term implications of these violations of the Hippocratic oath. The panelists are Dr. John Paul Sánchez.

Dr. Sánchez: Now more than ever, we need diverse individuals to become our faculty ... if we want something different in terms of who's teaching us, what's in our curriculum, how we rebuild trust with our communities, we need to assume the responsibility to serve in those leadership roles.

Unger: Dr. Michael Knight.

Dr. Knight: We're talking about communities who have seen centuries of being marginalized, of being experimented upon, being the left behind and have led to a level of distrust that's based on experience.

Unger: And Dr. Luis Seija.

Dr. Seija: For me in residency, one of the big things that I've learned is that our patients, especially Black and brown and those of color—they are well versed in racism when they're being treated different. And so, learning how to actually advocate for them and be that person to bridge trust, build a trustworthy system, falls on us as the trainees.

They unpack this history to better empathize, listen and advocate for patient concerns. This talk was recorded at AMA's 2022 Annual Meeting and was co-sponsored by the AMA Minority Affairs Section. Here's our moderator, Joshua Carrasco.

Carrasco: My name is Joshua Carrasco I am one of the co-chairs of the Minority Issues Committee, coming from San Antonio, Texas, rising fourth year. I think that this is a timely and important issue as learners and trainees in medicine, rebuilding trust among minoritized and marginalized communities through a narrative lens. Hopefully, this will allow you to walk away having learned something from these incredible individuals in their field. We're going to be defining distrust and providing some

specific incidences of historic and modern malpractice, medical malpractice examples faced by marginalized communities and identifying at least three ways, y'all, as learners and trainees can rebuild trust within communities that you're serving or within your communities in themselves.

So there recently was a study, a retrospective cohort study done from 2008 to 2017 about individuals that were going to the emergency room and figuring out who was being admitted to the cardiology service and who was being admitted to general medicine, all of whom were diagnosed with heart failure. And they found that Black and Latinx patients were significantly less likely to be admitted to the cardiac service. And why is that important? Because they found that admissions to cardiac service was independently associated with decreased readmission within 30 days, independent of race. So, anyone who is admitted to the cardiac service is having better outcomes. And so, the fact that Black and Latinx patients were not being sent to the cardiac service as frequently as their counterparts, this is a modern example of malpractice within health care right now.

I feel like distrust can sometimes be a nebulous concept but while racial and ethnic discrimination has laid the foundation, essentially to this medical distrust, like this Brigham example, we can more, I guess, tangibly define what medical distrust is. And as described by Laura Bogart, who studies the effects of medical distrust on HIV prevention and outcomes, medical distrust is a form of resilience and a self-advocacy on behalf of communities that have been harmed by the medical community. Essentially empowering them to seek health care reform and change at the institutional societal levels, which is not unlike most of our desires here in Chicago. Distrust can however be harmful to patients and communities when it prevents them from seeking care and health maintenance through our health system.

So today we have three incredible individuals and leaders within the respective fields of medicine and in diversity, equity, inclusion. If you could please take a moment to introduce yourself and share a bit about your experience with rebuilding trust among minoritized and marginalized communities throughout your time in medicine, please.

Dr. Knight: Sure. Thank you. I'm Dr. Michael Knight, internal medicine and obesity medicine but also serve as the associate chief quality and population health officer at GW, as well as the head of health care transformation but also working with our Minority Affairs Section as our chair.

And when I think about the trajectory of my career, when it speaks to this, even though I think these conversations have come to the forefront in the last two to three years, this is work that has been going on for decades and from my start in the Student National Medical Association and the MSS, and then through leadership in the AMA, have constantly been working to address this.

One of the things I want to start at because I think it's important for us to have a shared mental model when we talk about these concepts. Even when we think about the difference between the term distrust and mistrust, right? How many people know the difference between those two terms?

So, distrust is when there's a lack of trust that's actually based on experience or credible information. And mistrust is a general sense of uneasiness or unreadiness. And so, when we have this conversation, we're not just talking about communities that have a lack of trust because they're uneasy. We're talking about communities who have seen centuries of being marginalized, of being experimented upon, being the left behind and have led to a level of distrust that's based on experience. And so, when we have that understanding, we then more clearly understand our role as health care providers. When we see our patients that have a lack of trust, it's not coming from nowhere. And so, we start from there and say but what is our role knowing this information to overcome that?

In my experience as a primary care physician but also as a community health advocate, was mentioned is some of my work outside of medicine. I lead the Renewing Health Foundation, which is a nonprofit that I started as an intern when I was in residency, that works to do community education in urban minoritized communities. One of the critical things that I noticed when we started to go out to the churches, to organizations in New York City, where I'm from, is that I would say, "Let's do a talk about diabetes." And people would line up and have question after question after question. And I say, "Are these not questions that you ask your provider? Does no one here have a provider?" Everyone there had a primary care provider, had a health care provider. But they did not feel that they had a connection or a level of trust that was available for them to ask those kind of questions. And when we say, "Well, why is that?" We shouldn't just think about Tuskegee.

Because we talk about that all the time, as if that was the only thing, but that was just one example of things in our history and currently, in just showing the Brigham example, of why our patients feel like they have a reason to distrust the health care environment. We know that we don't come into medicine to treat people differently. The majority of us, 99% of us come into medicine because we want to help people. But we also have to understand the underlying implicit bias that are just ingrained in us, in just being raised in an unequal society. That unless we actively acknowledge it and actively put something into place to overcome that, our patients feel that. The Kaiser Family Foundation did a study in 2020 and asked African American patients, how many of them believe that patients are treated differently because of their skin color, because they're African American.

Over 70% said. Yes. They think that is a huge reason as to why. And so, if 70% of our patients are telling us that they feel like they're being treated differently, whether or not we want to acknowledge that we are doing it, something is there. Something that we are doing, they are perceiving and it's something that they're connecting to that. So, I know we're going to have a long conversation. We don't have that much time but I want us to just have that baseline so we can come in together, not pointing fingers, not in a defensive way but understanding that in a society that's not based on equity, it takes work to get there.

Dr. Sánchez: Excellent Michael. Well, Buenos Dias. My name is JP Sánchez. I serve as an emergency medicine practitioner but also as the executive director for the Latino Medical Student Association. And in my academic role, I serve as the executive associate vice chancellor for diversity and equity and inclusion at the University of New Mexico.

So, I would just touch upon three points. I think we all have narratives and stories of what brought you to medicine or public health. For me, it was really looking at how to address health inequities within what I call LHS plus communities, which is a variation on Latinx. LHS plus representing Latina, Latino, Latinx, Latin A, Hispanic or Spanish origin, just more inclusive umbrella term. But as a Puerto Rican, growing up in the Bronx, I would hear narratives and stories of what my people went through in Puerto Rico or in the Bronx, wherever Puerto Ricans migrated to.

And one of the most famous stories comparable to Tuskegee was the forced sterilization for the oral contraceptive trials that occurred amongst women on the island of Puerto Rico, before oral contraception were made available in the mainland. The first large human trial was amongst women in Puerto Rico. But what made it really distinct is that they particularly targeted women who did not have an education and were poor, which today would not happen because of the oversight of many IRBs. And unfortunately, many of those women endured sterilization and could not carry out their opportunity to have families. And that story is carried on within my community. And I think there's many other communities that have had similar experiences that leads to mistrust or distrust between us and the health care system.

So, one of the things that I found interesting going to medical school is that was never discussed. Those stories, those narratives, especially in being someone growing up in the Bronx and attending Albert Einstein College of Medicine, it really shocked me that there was not a space where this information was being shared or I could discuss it. But it also compelled me to explore how to change that. And I'll just leave you with two opportunities for you to think about.

One, how do we transform medical education? What is our role in serving as teachers in our classroom settings but also in contributing to curriculum content and to publications? It is your narratives, your lived experiences, the experiences of your communities that serve as exceptional submissions to journals. And one journal I'll point out is MedEd Portal. Uniquely, MedEd Portal, one of two journals of WAMC allows you to publish teaching materials and curriculum materials. And you as medical students, residents and fellows can serve as co-authors of that material and bring stories like La Operacion, Tuskegee into curriculum and have it integrated across the country.

The second point I'll make is, now more than ever, we need diverse individuals to become our faculty. So, as you know, although collectively, historically marginalized populations represent about one-third of U.S. inhabitants, only about seven to 8% of our faculty of our allopathic and osteopathic medical schools identify as Black, African American, LHS plus or Native American. So, if we want something different in terms of who's teaching us, what's in our curriculum, how we rebuild trust with our

communities, we need to assume the responsibility to serve in those leadership roles. AMA is a perfect example to serve and lead but don't forget the opportunity to become a faculty member or dean at our medical schools.

Dr. Seija: Howdy everyone. My name is Luis Seija. I'm currently a third-year resident, internal medicine and pediatrics at the Icahn School of Medicine at Mount Sinai in New York City. I'm a proud Texan as well. Just a little bit of where I'm at right now and with organized medicine, I came up through the MSS. Served as the Minority Issues committee chair and also the R3 and Texas delegation chair. I currently serve as the Minority Affairs Section delegate and I'm known for running my mouth.

But all for a good reason. And this is actually a very important topic and something that you, as learners and trainees, are in, like literally, in it. You see it every day onwards. You're exposed to it across many different specialties throughout all your different clerkships. And as medical students, it's important for y'all to take notes about what you're seeing and how you're seeing it and how those patients are being treated. You'll also have the time to sit, sit with them and learn with them, and learn about why they're being mistrustful or having those types of feelings.

As a resident, you're on the other side of things. You're the provider, you're the prescriber, you're the social worker, the case manager, all of it. And while you don't have the time, you start having those clinical correlations, like you build them a little bit more. For me, in residency, one of the big things that I've learned is that our patients, especially Black and brown and those of color—they are well versed in racism when they're being treated different. And so, learning how to actually advocate for them and be that person to bridge trust, I guess you could say, and build a trustworthy system, falls on us as the trainees. That's my personal opinion.

This last month, actually, I had the opportunity to rotate with the New York City Department of Health and Mental Hygiene in their Center for Health Equity and Community Wellness. One of the big things that I was very surprised about was this emphasis on community wellness and what they actually do to center community and equity. And how do they do that? They actually put communities in their driver's seat to help drive equity efforts. And the big focus of my rotation was increasing pediatric and adolescent vaccine coverage and rates and things like that. And so, there's a couple things that I took away from that whole entire month, which was probably the most grounding experience I've ever had in my life. But one, communities own communities. We are just guests, never forget that. And then number two, I wrote it down because I gave a talk and I'm really proud of it. So, hold on.

So, the national conversations about vaccine hesitancy often begin for the problem of mistrust, with an assumption that communities of color should trust medical providers and medical institutions. The onus is place of marginalized communities to unlearn their distrust towards medical practitioners. And the national conversation should shift from fixing people to fixing this system. It is important to recognize that given the history of medical discrimination and medical racism, trust is not the obvious

default for communities of color. Medical and public health institutions should work to becoming trustworthy by limiting biases, discrimination and having more diverse workforce. I think, for me, what am I doing right now? I actually just got a grant through ABIM to build trust in communities. And so right now, I'm looking at how can we, especially in the setting of the Cures Act, the 21st Century Cures Act—where patients can actually view what you're writing about them—how can we achieve health equity, social justice? And anti-racism in the electronic medical record. My goal is to liberate documentation. So that's what I'm doing. And what can you do? So hopefully after you've processed what we've set up here, y'all might have some ideas or we can give you some too.

Carrasco: Dr. Knight, we have a question for you. And it is, what strategies or approaches have you found to be most effective in rebuilding community trust through your nonprofit organization, the Renewing Health Foundation, and what stood out to you?

Dr. Knight: Thank you for that. I touched a little bit on some of the community work that we do with the foundation but I also want to go back to what Luis was talking about because I think it's so critically important that the default is not that our patients will trust us. I think that is what we don't always understand because we put on our white coats, whether it's short or long. We walk into the room, "I'm Student Doctor So and So, I'm Dr. So and So," and automatically, why wouldn't this patient trust me? I have on the white coat, I have my degrees, my credential, show on my badge. You should automatically see MD, student doctor, I trust you. But when we understand the history, when we understand the common experience and understand we're coming to a situation where that may not be the default that puts the onus on us to really show why that person should trust us.

This is a great article that came out in the last two years, and you can look it on PubMed, it's called "Trustworthiness Before Trust." And I think it's excellent because it outlined that as a health care industry, our role and responsibility is to show that we are trustworthy, not to expect that patients will just trust us. And so, when we think about the work that's done in the community, it's always going in and saying, "Look, what are your needs? What do you want to get out of this interaction? What can we do to build that trust?" If someone's from the community, who looks like that community, it may be easier for me to build trust but that does not mean that anyone cannot build trust. Any provider can build a relationship with any patient from any background. If they come into that relationship with humility and with understanding to know that I have to put in the work to build that trust.

One of the concepts, I think that really explains what many of our patients see is something that's called cumulative de-prioritization. So, if you haven't heard of it, definitely look it up. It's actually fairly new that came out on Med Twitter about a year ago. But I think it really explains what people see. And so this is what it is. In medicine, we make decisions all the time. It's a constantly making decisions, constantly triaging patients for various things. So, which is the patient I'm going to spend an extra 15 minutes with to discuss this? Which is the patient that showed up 20 minutes late, that I'm still going to see? Who am I going to call back immediately? Who am I going to call back three days later? Which

patient are we going to take to the ICU when there's only one bed and three patients are crashing on the floor? Which ER patient am I going to see first? All of those decisions not only include what that patient is presenting medically.

It also includes how we subconsciously view that person and the value of that person. And so, what our patients are actually feeling is why are you spending so much time with that patient and I've been waiting for three hours in the ER, no one has talked to me? Is it because of how I look? And that's the first thing that comes from because they say, "This is how I feel when I go to the bank and when go to the grocery store. And when I go down to get my check. And when I'm talking to my landlord." It's the same thing. So, our patients know when we just talked about that. They are experts in knowing when they are not being treated the way that others because they see it every day. And so, as community organizations, what the foundation is doing, as a health care provider, I have to understand that. And then I have to be intentional in saying, "Why am I treating this patient differently than that one? Why is it that I'm going to respond to this call before that one? Is it because of how that person looks? Is it because of how I'm valuing that person? What is it?" And I think that really brings that conversation and unpacks, how we interact with patients and what they're perceiving.

Carrasco: Dr. Sánchez. So, given your extensive experience working in medical education, we'd like to know what role does MedEd play in rebuilding trust among marginalized communities and how might pipeline programs fit into these efforts?

Dr. Sánchez: Great. So, I touched upon that already, I jumped the gun and it gave my full response. I'm really about providing resources, so as mentioned, MedEd Portal. MedEd Portal. I feel like for me, it's really created a unique space, not only to elevate the voice of communities but also to help medical students and residents publish. I think more and more journals are creating spaces where medical students and residents can serve on the board. That didn't exist when I was a medical student, most people on editorial boards were established faculty. So that you could step into these spaces, write about your communities, write about the historical but also the present.

There's plenty of examples I can give you right now of what's going on, where I grew up in the Bronx, that harp on similar scenarios, like in the 1950s or the 1960s. And just one other thing I'll mention, there's a new national center for pre-faculty development that consists of 25 medical schools. And the purpose of this National Center for Pre-Faculty. Like pre-med, pre-nursing, pre-fac is to help you in exploring what it would be like to become an administrator within a medical school.

Carrasco: Dr. Seija, this last question is for you. So, for those of us graduating soon, how can residents further these efforts to build trust with our communities? You did mention this prior but I feel like you may have something else to say.

Dr. Seija: So, I think it's about shifting the framework in how we view things. So, to Dr. Knight's point, the default is that patients don't trust us but I would argue that we don't trust patients. And really you

need to look in the mirror and look at, just because you're a doctor does not mean that you're going to save the world and heal all the communities or any of these other things. I think we have a new generation of physicians that really recognize that but there's still a lot of work to be done. And that taking an implicit bias course is the bare minimum that you can actually do. And especially for all our white colleagues out there, the onus is on y'all, truly, to do the work and to really dig deep and say to yourself, "It's not enough to be non-racist. I need to be anti-racist." Change things from, you know, to active verbs.

How am I saying? What am I saying? How am I documenting that? Especially in this era of the open notes. How would you want to be perceived? You know, do you want to have your one ... think about what your one-liner is. Do you want it to say Black, Caucasian, all these other things? How is that relevant? Because that actually puts in a whole bunch of different conceptions from the get-go when you add race and race-based medicine and all these other things. And so, and as a resident, just take the time to talk to your patients. There's lots of pre-rounding, there's lots of labs to follow up on. There're discharges, all these other things. But when you take that step back, go back to the patient room, ask them one of the most enlightening things I can ever ask a patient is, "Like, do you know why you're here?"

Because that will just spark a whole different conversation. I had a patient that was being worked up. They were transferred to Sinai for a liver transplant. And I asked him, "Do you know why you're here?" This was like on day five; I felt so bad. It was just a crazy service. And he said, "Oh, yeah, I have high blood pressure." And I was like, "Oh, okay. We really got to work on that." And so, while you're working on your assessments and plans, medically, but also be very conscious about the psychosocial factors that brought them into the hospital in the first place.

Carrasco: All right. Thank you all for being here and speaking with us. I hope you all have a great rest of your day.

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