

Transcript Details

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Discovering Disparities in Diversity: Representation in Clinical Trials

Dr. Caudle:

Although Latinos are one of the fastest growing minority groups in the United States, they represent less than six percent of physicians, and female Latinos make up an even smaller fraction of that. So, to help address this disparity, a progressive social movement known as #LatinasInMedicine has formed a new space for Latinos actively practicing medicine, along with prospective students, to connect and amplify their careers and accomplishments. With over 5,000 members, this group has proven it's here to change the status quo. And today we're going to speak with one of the three co-founders of this trailblazing initiative.

Welcome to *Clinicians Roundtable* on ReachMD. I'm your host, Dr. Jennifer Caudle. And joining me to discuss the underrepresentation of minorities in clinical trials and her fight for cultural change is Dr. Narjust Duma. Dr. Duma is a medical oncologist and assistant professor at the University of Wisconsin School of Medicine and Public Health in Madison. She's also the co-founder, along with Drs. Briana Christophers and Maria Pinzon of the #LatinasInMedicine.

So, Dr. Duma, welcome to the program. We're excited to have you here.

Dr. Duma:

Thank you so much for having me. I'm looking forward to our conversation.

Dr. Caudle:

I am as well. So, to kick off our conversation, Dr. Duma, can you give an overview of the patient representation of most clinical trials? And is this consistent among most or even all specialties?

Dr. Duma:

So, the majority of my knowledge comes from oncology, that's my subspecialty, that's one of the studies that I have done. particularly now with the pandemic in the vaccination trials, we also have some knowledge about that. So, I won't generalize to all the specialties as I have not reviewed each one, but the main issue that remain is that the majority of clinical trials continue to recruit a majority of patients that are part of the majority group. And there's not only differences about race and ethnicity, but also about gender. So, majority of studies have recruited patients that self-identify as white and males. And in oncology, this is significantly important because most of these drugs are quite toxic, so we are recruiting only a subgroup of patients and then we are extrapolating all that information to the rest of the population. So, in the case of oncology, we have trials that have recruited 1 percent or less of Hispanic or Latinos in clinical trials, despite being around 17 to 18 percent of the population. When it comes to African Americans and Black, then the numbers are significantly low, even for diseases like multiple myeloma in which the frequency is higher, the incidence is higher, in Blacks and African-Americans, they're still the minority of patients being recruited in the clinical trials. So, that also has been reported in cardiology clinical trials, and it has been reported in some of the rheumatology clinical trials. So, I won't generalize to all the specialties, but I think it's a general problem in medicine in which we collect data for the majority group. And then that data is utilized to treat patients of all different racial and ethnic backgrounds.

Dr. Caudle:

And as a follow-up to that, Dr. Duma, why is there a huge misrepresentation in our clinical trials? And can you speak to the lack of trust that may keep some people from participating in a trial?

Dr. Duma:

So, there are several factors that affect this huge misrepresentation. One is the majority of the clinical trials take place in large academic

hospitals in cities where patients do not get care, like minority patients and older adults do not get care. Most minority patients tend to get care at smaller hospitals, something that we call safety net hospitals, in which they feel more comfortable because generation after generation has gotten care there or they don't have a history of mistreating patients of color. So, one is the clinical trials are very centralized. There are limited clinical trials in rural parts of the U.S. And even in large cities like New York City, the clinical trials are located in the main hospitals, not the main, but the larger ones. And the hospitals where Blacks and Hispanics get care usually don't have the same portfolio.

Another reason of the misrepresentation is physician bias. And we all have unconscious bias. And this is associated in which the physician may take the decision of not offering the clinical trial to the patient because there's a perception that they don't want to be part of it. And when you add a language barrier for Latinos or Latinx, then the physician bias multiplies. Oh, this patient will not understand what our clinical trial is. Oh, this patient will not understand this.

And it's important to mention that many clinical trials do not have consents in Spanish, despite being the second most spoken language in the country. So, it is unfair to try to consent somebody who doesn't speak English with an English consent.

And finally, the mistrust issue that you brought up. There is historical events and there are current events or how the healthcare system continues to fail minority populations. COVID-19 is a reminder of all these disparities because they were very wide and they continue now with vaccination. When the healthcare system continues to fail you, will you trust it? And I think we ask too much of the populations of color to trust a healthcare system that continues to marginalize them and mistreat them. So it's not about trust, it's about us not gaining their trust or losing it through historical events.

Dr. Caudle:

That's very well put. You know, you talked a little bit about this before, but I would definitely like to revisit it.

If we look at the results seen in trials comprised of predominantly Caucasian participants, are we to just generalize that these trial results can be applied and accepted for all ethnicities and genders? I have a feeling that we know the answer to that. But I would love for you to expound on that. And can you also talk about what issues can materialize from this occurring?

Dr. Duma:

So, I'm going to use an example. So, yes, we use the data, this predominantly male Caucasian participants. So, it's not only a matter of race and ethnicity, it's also a matter of gender. One well-known example is benzodiazepines. The data from long-acting benzodiazepines was collected in a majority male white population. And then we learn when the drug was approved and, in the market, that women have poor tolerability. There are horrible stories about it. And then the drug needed to go back and have a dosing that was more appropriate for women.

In the case of cancer drugs, these are drugs that will potentially save somebody's life or make them live longer. But when you have data from one group, you don't really have data about, does it really work that well for Blacks? Does it really work that well for Native Americans? We don't know. And then we keep giving patients numbers that, in part, are lies because these median survival or these overall response rate are from populations that are not our patients. And my interest in it started all with an African-American patient that keep asking me, what about me? When I was, you know, repeating all the data from the trial. And when I finally asked and he say, what about Blacks? Were there any blacks in the study, how they did? And I remember going back to one of the largest landmark studies in lung cancer and figured out that was one black participant out of 1,000.

So, the problem is that we then don't know how well these drugs work for certain populations. We are genetically different. We metabolize drugs differently. And so we're saying, no, these drugs is 80 percent effective, but is 80 percent effective in Blacks? We don't know because we're not included in the studies. And another issue is tolerability. Are patients able to tolerate, are we telling them adverse events?

And one example of this is skin reactions. Skin reactions are very different in people of color. So, what is the real percentage of skin reactions in people of color with immunotherapy? Well, we don't know because there was only a handful people of color in several studies all put together.

So, the problem is we are treating our patients with drugs that may not be as good for them or they may be potentially more toxic.

Dr. Caudle:

For those of you who are just tuning in, you're listening to *Clinicians Roundtable* on ReachMD. I'm your host, Dr. Jennifer Caudle. And today I'm speaking with Dr. Narjust Duma, co-founder of #LatinasInMedicine.

So now that we've talked about how underrepresentation in clinical trials is widespread across all specialties, I'd like us to talk about what can be done to address this disparity. So how can healthcare professionals and leaders make the intentional change to ensure that

minorities and all genders are equally represented in clinical trials?

Dr. Duma:

So, I think when we talk about this, there's always the decision like, oh, there should be a policy. But I strongly believe that us, as healthcare providers, we have a role in generating equity and we all can generate equity. You know, it is not the government, it's not the institution's responsibility. It's our responsibility and duty as well. So, the first thing I ask all healthcare professionals is ask patients of minority groups about their interests in clinical trials. Because the main obstacle is that patients are not being asked. And that's a cheap solution. And when we talk about health disparities, most solutions are not cheap. And this one, it is. Just ask them. Don't come with preconceptions that, oh, Blacks don't participate in clinical trials. Really? Like have you asked that patient? Every patient is very different. And for the patients that are presented with the opportunity clinical trials and say, no, just explore the reasons why. There's a lot of perceptions that sometimes patients just get a sugar pill, and they won't get treatment. But in cancer, for example, which is my specialty, no cancer clinical trial goes with placebo. They all have an active treatment. So, it is important to explore that.

And secondary, when we are reviewing articles, when we are part of the editorial boards, that all those clinical trials are submitted. Should submit the data about race and gender, not only in the Table 1 of demographics, but also subgroup analysis, like do you evaluate if this drug is as toxic in women versus men? And women are the majority of the population, but we don't really have any data about if they do well or not. And in part, many of these drugs were a study in male cell lines. So, the disparities start at the bench and they multiply as the drug continues to move forward.

Dr. Caudle:

Very good points. You know, earlier you spoke about the lack of trust that some patients may have in the healthcare system. So how can we as healthcare professionals, build back this lost trust? And how can this lead to more participation from underrepresented minorities?

Dr. Duma:

One important thing is that we have to practice cultural humility. And that is what is going to help us build back the trust, as physicians. And when I'm talking to you, I'm talking about what our listeners can do themselves, instead of just, you know, saying the institution should do it. So, cultural humility comes from the concept in which we are open to learn from other cultures, and that one thing is not better than another, because what is accepted in one culture may not be accepted in another. And that we're always growing as physicians and human beings. So, I invite anybody who's listening to read a little bit more or just watch a YouTube video about cultural humility. Cultural humility is when we come for a place of learning instead of a place of misconceptions or unconscious bias. So, that will help with the trust. I know the thing is that it is important that we are there for our patients and we advocate for our patients. And that we help build the trust. Because when a healthcare system continues to fail a group, that group not only needs one advocate, it needs thousands of doctors that would be advocates. So, advocate for your patients of color, they have more barriers. And it has been proven over and over in many studies. We don't need more studies proving the challenges. We need more people being active allies for minority groups.

Dr. Caudle:

That's very well put. And before we wrap up, you've said so many things. I think, you know, we all need to hear and our listeners will benefit from. But before we wrap up, I'd love to hear any final thoughts you may have to share. And honestly, how can we also find the hashtag Latinas in Medicine online community? I think this is a really wonderful community that you've built. So if you can expound on any final thoughts and how we can find you all and learn more.

Dr. Duma:

So, Latinas of Medicine was created with my two co-founders because we're isolated, and often the only Latina at the table even given a chair at the table. But when isolation is very common. We are 1.8 to 2 percent of physicians in the U.S. despite being one - second largest growing population in the country. So, the community was created to help with the isolation that many healthcare professionals feel, and also to serve as role models. You can do what you can see. Over and over again, I get messages from younger Latinas that they're like, oh, I didn't know being a doctor was an option. And that just sincerely breaks my heart, because if you're born in this country, the opportunities are endless. But for some Latinas, those possibilities never have been proposed or told that they can do it. So, the Latinas in Medicine Community is a Twitter community that, as you mentioned, is over 5,000 members. We have interviews in which we highlight Latinas in medicine. We have a way to connect with other Latinas. We have created this community, so you don't feel alone because we are many. We're just not many in the same institution.

And finally, we also have served as a connection for mentorship in which younger generations of Latinos can connect with more senior Latinas you may not receive mentorship in your specialty, but just mentorship on how to manage medical school, how to navigate residency, how to feel comfortable in your own skin. Because we're often told, and I've been told many times, that we don't fit the box

that what a doctor's supposed to look like, because the unconscious biases are out there. So, it has been a great experience. We are two years old now and hope in the future we will have our own conference. And the way there's a house for the Latinas of medicine all around the world to know that they're not alone and that we're here to change the status quo.

Dr. Caudle:

Well, it's very exciting. I'm not Latina. I'm African-American myself. But I just went on Twitter and I just followed your Twitter page and look forward to really great posts. So, appreciate you bringing this community to all of us because it is so important.

You know, this brings us to the end of today's program. And I'd really like to thank you, not only for joining me today and sharing your thoughts, but for really doing such important and excellent work in the medical community to help combat these disparities. It was really great having you on the program.

Dr. Duma:

Well, thank you so much, Dr. Caudle. I hope one day we can meet in person.

Dr. Caudle:

Absolutely. I do as well.

And I'm Dr. Jennifer Caudle. To access this episode and others in our series, please visit ReachMD.com/CliniciansRoundtable, where you can Be Part of the Knowledge. Thanks for listening.