

# Beyond Race and Ethnicity: Social Determinants of Health and Disparities in Rheumatology

## Transcript

**Iris Navarro-Millán, MD (Guest):** Why are we in the health care system that treats people differently? Collecting systematic data on social determinants of health will be important for us to know where to identify actionable gaps in health disparities.

**Meghna Rao (Host):** Welcome back to season 2 of the *Rheumatology Advisor* podcast, *Rheum Advisor on Air*. I'm Meghna Rao, the senior editor of *Rheumatology Advisor* and the host of this podcast.

In this series, we will be joined by expert clinicians and researchers to discuss emerging and compelling topics in rheumatology. These perspectives may be related to the management of rheumatic disease, guideline updates, patient care, data from conferences and scientific meetings, and much more.

In the next set of episodes, we're talking with some of the presenters of the all-virtual American College of Rheumatology (ACR) Convergence 2021.

So, let's dive in!

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**Meghna:** There are plenty of available data on the racial and ethnic disparities in rheumatology in the United States in terms of epidemiology, disease activity, and socioeconomics.

Now, at a recent ACR 2021 session, Dr Iris Navarro-Millán and Dr Ashira Blazer highlighted certain aspects of health care disparities in rheumatoid arthritis and lupus respectively, including why these inequalities exist on different levels, what the gaps are, and how the system can be improved in this regard with the help of well-tailored interventions.

Today, we are joined by the wonderful Dr Navarro who is an assistant professor of medicine at Weill Cornell Medical College, New York, and a rheumatologist with an expertise in rheumatoid arthritis.

Hello, hello! And welcome, Dr Navarro.

**Dr Navarro:** Hi. Thank you for the introduction and thank you for having me today.

**Meghna:** Of course! Are you relieved that the ACR meeting has finally concluded? It was a really long one this year!

**Dr Navarro:** It was a really long one, and it was totally worth it; it was

fantastic actually.

**Meghna:** You told me that you loved the virtual format, and, as a reporter, I couldn't agree more. But how was the conference this year? Were there any sessions you particularly enjoyed?

**Dr Navarro:** I've always enjoyed the evidence *[sic]*, the review courses, [and] the plenary sessions. I loved the hubs this year actually; I thought that the Community Hubs was a big ask *[sic]*, a bit hit – it had a lot of resources and useful information for the clinicians. So, I tried to put [on] my clinician hat when I go into the ACR, be a great attendant, and pay attention to what others are doing more than show what I'm doing. Because this is the moment of the year when you get to learn a lot from your peers.

**Meghna:** I also think there was such a wide range of very interesting topics and speakers this year.

In your presentation itself that happened on Sunday, November 7, I was really intrigued by your description of the patient encounter that you started out with. It really brought the patient voice to the forefront. Dr Navarro, could you elaborate a bit more on this incident that speaks to the existing health disparities in our health system?

**Dr Navarro:** Absolutely. It's interesting because this patient made that comment when we were closing the encounter. We were just giving the final instructions, the next steps, and follow-up. And I asked, who is your primary care? Asking as a "he" primary care, and I said, I'm sorry, or "she" primary care. She replied with the answer that I only see females or female doctors because they are the only ones [who] see me as a human.

It was alarming to me. It was alarming in several ways because why are we in a health care system that treats people differently, or even consider some other human beings not human?

And I think the other part that resonated with me about her comment – there were 2 other things. One of them was, am I doing the right thing and making sure that everyone feels warmth with me and [receive] care as a human. And the other thing was yeah, I hear you, I've been in those shoes. I am a Hispanic woman, a woman of color, and I did encounter that kind of profiling within the health care system; that is why it was alarming. So, you see where you put yourself in both positions, as a physician and as a patient. That is why I'm very passionate about this topic.

So, I think that reflects on how the issues of disparities exist, and until we experience that ourselves, sometimes it's hard to understand it. But we are making progress about sitting at the table with people [who] have not experienced health disparities to communicate this type of messages – like the message from this patient – to say, here it is; there is a problem and I invite you to sit at the table with me to have a conversation about how to change it, so everyone gets treated the same.

**Meghna:** Wow that is a really hard-hitting incident, so to speak. I can also resonate with what you said.

But you know another thing that really stood out to me in your presentation was your reference to the advocate for women's minority groups in medicine, Dr Bernadine Healy. How has her work had an impact on your approach to patient care in rheumatology?

**Dr Navarro:** You know, Bernadine Healy was a very special woman. I think, to date, she was the only female director of the [National Institutes of Health] (NIH). But I don't know if you know this, in the NIH, it not necessary or as a mandate to include women in clinical research. This did not change until she became the director of the NIH. When you submit a grant proposal to the NIH, you have to promote a statement that you are going to make every effort possible to include women and underrepresented minority groups. And that effort was started by her. So, that is why I thought of her example in health care – something that we can emulate, we can replicate in our time, and say, where is our contribution to make that cultural lasting change that she also talked about doing her time; and she achieved it.

So, to me, it's like, when is my Bernadine Healy moment, right? In my career, in the way that I treat my patients and in the way that I'm making every effort in my research agenda, my research portfolio, to be as inclusive as I can be.

**Meghna:** I absolutely love that, and I have no doubt that your moment is going be here really soon.

**Dr Navarro:** We make a little bit day by day, right? I think sometimes it's not a moment precisely, but it's just [baby] steps; I like to call that baby steps!

**Meghna:** Absolutely. [Now], getting down to the specifics on race and ethnicity – let's start with why race and ethnicity are important to differentiate between in studies?

You know, when reporting data at *Rheumatology Advisor* and other publications, we are mostly aligned with the [American Medical Association] (AMA) style. And something that's been coming up more and more commonly now is how to use patient-sensitive and inclusive language with regard to race and ethnicity among others, even though we only offer clinical content. But I guess what I'm trying to say is I'm sure a lot of us will benefit from this conversation that you brought up at the meeting, so thank you.

**Dr Navarro:** So, yeah, that is a very interesting topic. I think that there are several points to make a distinction here. It came in another of the ACR meetings that if we don't see race [or] we don't hear about race, we don't talk about race, right? So, if we don't address or identify some of the problems then how [can we] fix them? And that is the intention that I had when I was bringing up the topic. Yes, race is a social construct and ethnicity is a matter of culture background that can be the Hispanic or Jewish community, or the

Muslim community, [who have] several aspects in their daily life tied to their [religious] beliefs.

So, I think that having an understanding of individuals' background and beliefs will and does improve their care; we know what [their] priorities a little bit better, and we also know in which areas they had probably suffered some level of social injustice. Because as I said earlier, these are social constructs but [they] also are reflective of the social system that we have that had to some degree, at different levels, deprived certain groups from resources from care, from education, and so forth, [which] can affect their health.

That is why it's important to bring those within the aspect of clinical research and basic science research, so other environmental factors can be taken into account.

**Meghna:** And just to add to what you are saying I want to bring up here what you mentioned on Sunday at the meeting about the incorporation of aspects of race and ethnicity in research and clinical trials, and possibly, even rheumatology practice guidelines.

**Dr Navarro:** Absolutely. One of challenges is that we make a blanket statement. And that is what I would caution the audience that it's not only about if you belong to this race or this ethnic group [that] by default you are "this" way or "that" way, right? It's not genetic makeup [that] makes you by default predisposed or not predisposed to [an] issue, but [it is] also to the social environment. That social environment has to look beyond the phenotypes of race and ethnicity.

The way that you get to understand that better is by following a systematic, strategic, data collection of social determinants of health. By doing that, what I have found is that most of the issues that my patients encounter, while yes they are related to race, some of the others are actually about housing insecurity and food insecurity. Some of my patients are living in friends' houses because they cannot afford to live in their own house and pay their own rent or mortgage. Can you even imagine the level of stress that a person living that like could lead, or could be with, [and] not having their own bed?

So, that is why I was going into looking deeper, and not limiting it to race and ethnicity only.

So, social determinants of health is very important. I have found that housing issues are probably even a bigger problem, at least that I have encountered in the daily living of my patients, than racism itself. Of course, racism is still high up.

**Meghna:** To be honest, I don't often think of these aspects as contributors to existing disparities, but it obviously underlies the importance of open communication and patient engagement, which, Dr Navarro, we can all look up to you. Your goal of building these meaningful relationships with your

patients is inspirational.

But is there any specific guidance in this respect that you can offer to providers so they can start to address these issues as they observe them?

**Dr Navarro:** So, there are different strategies that I use, and I think the biggest teacher has been experience to me, seeing a lot of people from all kinds of backgrounds. Some people [have physical disabilities] by the time I see them for the first time, and, at that point, sometimes, we just really focus on the symptomatology – the clinical presentation, the need to be able to move around. Fine. And then, in some instances we can even focus the first encounter on, like, tell me about your housing status? Are you working right now? Tell me, what kind of work do you do? And are these symptoms impairing or limiting your ability to do your work? Most of the time they do [open up] because these are musculoskeletal disorders.

I'm very committed to keeping my patients with arthritis in the workforce. For me, that's how [I] have succeeded as a rheumatologist. And sometimes that is the only thing that you have to start talking with your patients to open up about other aspects of their social lives. They start talking about their spouses, their children, their housing, and how they're sometimes having 2 to 3 jobs to bring food home. Sometimes, it's a good strategy to let the patient open up to you, right? But sometimes we have to open the door and welcome that kind of conversation. It's very easy to do so, and it has worked very nicely for me.

Now, some people are retired [and] they cannot live an independent life. Then that's when I go, what kind of help do you have at home? What kind of family can help you do several things? How do you do your groceries; tell me more about that? In that way, you are welcoming them to trust you because this is a matter of trust so that they can also feel comfortable and that you genuinely care, and not just to fill the boxes in the medical record to say this is what I need to collect for the physical, but something that you can hopefully act on, which I'm very fortunate to be able to do in my practice because I live in New York City. New York City has a lot of social networks and resources for members of our community that our social workers can provide to our patients that have some needs.

Talking about work and their daily life is very important, so they can enjoy every single day [i]n their life, and age and live with dignity. That's my motto.

**Meghna:** Yep. Yeah, absolutely. You also spoke, in your presentation, about the patient-activated learning system or PALS that your team developed based on the idea of improving health literacy and the shared decision-making process between patient and provider.

**Dr Navarro:** Actually, the patient-activated learning system was developed by my mentor and boss, Dr Monika Safford in the Division of General Internal Medicine at Weill Cornell, and it came from her experience working in rural

Alabama with Black women with diabetes. [Dr Safford] is a health disparity researcher and as a need from the community, she developed this program to educate people and have self-assessment questions – like we do continued medical education for doctors, but [this is] for patients. It has a see-the-science [*sic*], it is evidence-based; the patient-facing text [is in] sixth-grade language, so everyone can understand, or some of them might also have videos. Animated videos have 1 minute [or] a minute and a half information that patients can act on. That's why it's called the patient-activated learning system.

Do you need a cholesterol test? Talk to your doctor. Do you want to find out if you have diabetes? Talk with your primary care. So, there is always a call-of-action in PALS. Right now, we have a couple of interventions where we are testing how PALS performs by itself and also how PALS performs guided by a peer coach, which is another person with rheumatoid arthritis.

It's an ongoing project, so I cannot tell you too much beyond that. Hopefully by the next ACR we will have some preliminary data on that, but we have several patients enrolled in this study to test how this actually does. So far, PALS by itself is still performing quite well in activating patients to change behaviors and engage more in their decision-making for their care to the point that they are also leading to change in physicians' behavior, in the way that physicians are seeing how committed and how practical [*sic*] they have to be in several decisions that they have to [make] for their patients.

Very interesting. So, probably be coming for ACR 2022; how about that?

**Meghna:** Yes, absolutely. We'll do another podcast episode on that. But, you know, that's all so great.

You ended the presentation on Sunday on a rather wonderful note, I must say, with the action words – research, involve policy, and diversify. In your opinion, will these be the measures that take us 1 step closer to achieving health parity in rheumatology?

**Dr Navarro:** [T]he reason that I have come up with this working is because as enthusiastic as I am for health disparities, sometimes, it also has been a little bit daunting to see the change to happen, right? We see a lot of papers coming out pointing fingers and calling out people, [and] how unfair you have been, and so forth. So, I don't want my contribution to health disparity to be [of] that kind; I want it to be something that takes action and whatever action and change I can achieve in my time, I can achieve it. But I know that I cannot do that alone.

So, that is why I invited the audience and I invite your audience, too, to engage in research. Because collecting systematic data on social determinants of health will be important for us to know where to identify actionable gaps in health disparities.

Sometimes it's also important to understand the community that our patients

come from. Because it's *[inaudible]* and everyone has [d]ifferent circumstances that are limiting their ability to engage in clinical care and participate actively in their care. And again, our care is guided by health care policy and health care delivery policies. As a result, we need to make sure that every single challenge that we have – not every single challenge, but many of the challenges that we have – in clinical care [speak to] how are these influenced by the ways that policies in the health care system have been implemented, so that we can change it. And sometimes it's as easy as having more conversations and bringing some of these issues to the attention of pharmaceutical [companies], health insurance, and, in some instances, mayor, governor, and all the way up. But it's important to tie our work to policy because that is when we achieve lasting change, actually.

To me, diversification of the workforce also implies that diversity in knowledge, diversity in experiences for the members of the workforce, [and] diversity in solutions that we all bring to the table.

So, I think that these are actionable words. I wanted to give the audience the actionable words that I keep in my mind on a daily basis. That was the intention behind [t]his construct.

**Meghna:** Incredible. Dr Navarro, those are some pearls that we hope, actually I know, will make an impact in the area of health disparities in rheumatology.

It's safe to say the emphasis on the role of social determinants in health, including socioeconomic background, education, [and] access to health care, and how these factors can play a major part in the provision of adequate patient-centered care.

I just want to leave us with – I don't think I could have said it better than Dr Candace Feldman who at the end of your session said – “Hopefully, this is the beginning of many such conversations.”

**Dr Navarro:** Absolutely. I look forward to continuing to talk more and probably the next time that we talk, we talk about what [we have] achieved.

**Meghna:** Absolutely. And shout out to Dr Ashira Blazer as well for her definition and interesting compilation of race during the same session. I thought it was great overall.

**Dr Navarro:** Absolutely; it was fantastic.

**Meghna:** Thank you so much again for joining us again, Dr Navarro. It was an absolute pleasure.

**Dr Navarro:** Thanks for having me.

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**Meghna:** Please stay tuned for more episodes in this series. For more information on *Rheumatology Advisor* and this podcast, you can reach out to us at [editor@rheumatologyadvisor.com](mailto:editor@rheumatologyadvisor.com).

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