

Tacking Arthritis Challenges for Patients of Color

 Hosts: Rebecca Gillett, MS OTR/L, Director, Content and Strategy, Arthritis Foundation Cristina Schaefer, Arthritis Advocate and Patient
Guests: Ashira D. Blazer, MD, MSCI, Assistant Professor of Medicine, Weill Cornell Medical College Michael Parks, MD, Clinical Director of Orthopedic Surgery Hospital for Special Surgery

About the Episode

People of color face more challenges when it comes to managing arthritis, including delayed diagnosis, issues with doctor-patient communication and under-treatment of pain. Achieving good quality of life with arthritis can be made even more difficult to due myths and knowledge gaps about arthritis, including the importance of early aggressive treatment, medication adherence, joint surgery and more.

This episode's experts will help us understand more about the role that health disparities play in arthritis care and their origins. They'll also discuss various barriers to care, including lack of trust between patients and doctors and socioeconomic factors to health, and provide solutions so that minority patients can take control of their arthritis.

About the Guests

Ashira Blazer, MD, MSCI

Dr. Ashira Blazer is an Assistant Attending Physician at the Hospital for Special Surgery and Assistant Professor of Medicine at Weil Cornell Medical College. Before that, she was an Assistant Professor at the New York University School of Medicine in the Division of Rheumatology.

Dr. Blazer specializes in the treatment of all rheumatic diseases including inflammatory arthritis and systemic lupus erythematous (SLE), particularly in patients of African ancestry. Her research focuses on the impacts of genetic, environmental, and social factors, which she uses gather insights for personalized treatment options for this patient group.

Dr. Blazer has been recognized by the National Minority Quality Forum as a Top 40 under 40 leader in minority health. She is also a thought leader in SLE disparities and has served in leadership roles for the American College of Rheumatology, Lupus Foundation of America, Lupus Research Alliance, Association of Women in Rheumatology, African League of Associations for Rheumatology, and Lupus Nephritis Trials Network Among others.



Michael Parks, MD

Dr. Parks is associate attending at Hospital for Special Surgery (HSS) and associate professor of Clinical Orthopaedic Surgery at Weill Cornell College of Medicine in New York. He specializes in the surgical treatment of adults with arthritis requiring reconstructive procedures of the hip and knee.

Dr. Parks has led a number of research projects at HSS, with a particular interest in socioeconomic and racial disparities in access to arthritis care and total joint replacement surgery. His research has published numerous journal articles related to joint replacement outcomes and racial differences.

Dr. Parks has also been recognized for his expertise in numerous publications throughout his career, receiving top doctor rankings in Black Enterprise and Money magazines. He has also been recognized in such publications as The Network Journal, The New York Times Magazine, and Castle Connolly's Best Doctors: New York Metro. In 2019, he was the recipient of the American Academy of Orthopaedic Surgeons' (AAOS) Diversity Award.

Recently, Dr. Parks was named treasurer of the AAOS. He has served as president of the Orthopaedic Research and Education Foundation (OREF) and is a past president of the New York State Society of Orthopaedic Surgeons. He previously served on the AAOS Board of Directors and the American Association of Hip and Knee Surgeons (AAHKS) Board of Directors. He is on the steering committee of the Movement is Life Caucus, a multi-stakeholder group devoted to decreasing musculoskeletal healthcare disparities.

Additional Resources:

CDEC Health Disparities and Inequalities Report

Health Inequality Actually Is a "Black and White Issue", Research Says

How to Find an Anti-Racist Doctor



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PODCAST OPEN:

You're listening to the Live Yes! With Arthritis podcast, created by the Arthritis Foundation to help people with arthritis — and the people who love them — live their best lives. If you're dealing with chronic pain, this podcast is for you. You may have arthritis, but it doesn't have you. Here, learn how you can take control. Our host is Rebecca Gillett, an arthritis patient and occupational therapist, who is joined by others to help you live your Yes.

MUSIC BRIDGE

Rebecca Gillett:

Thanks for joining us on this episode of the Live Yes! With Arthritis podcast. Communities of color face an unequal burden of arthritis. With nearly 60 million people living with arthritis, we know arthritis does not discriminate. A delayed diagnosis, communication challenges with health care providers, dismissal and undertreatment of pain are just a few of the obstacles that people might face.

Yet, arthritis pain can affect so many aspects of living on a daily basis, including our emotional health, our work, relationships and family responsibilities. Trying to find that good quality of life when you live with arthritis can be made very difficult due to misinformation and knowledge gaps about arthritis, the importance of early, aggressive treatments, medication adherence, surgery when it's needed and living a healthy lifestyle.

So, we have today some guest experts to discuss what the origins of health disparities are when it comes to arthritis — and provide some strategies to help minority arthritis patients learn how to take control. I'm happy to have one of our amazing volunteers with the Arthritis Foundation be a guest cohost with me on the podcast today. Cristina Shaeffer is joining me in this conversation. Cristina, can you just share a little bit about yourself with our listeners?

Cristina Schaefer:

Absolutely, Rebecca, thank you so much for having me. As you said, I'm a volunteer with the Arthritis Foundation. But my story starts about 18 years ago when I, at the age of 20, was diagnosed with rheumatoid arthritis. I struggled for many years to find the right kinds of medications that could help me live. I'm finally in a good place again and able to volunteer more of my time with the Arthritis Foundation.



I serve on a few different committees, one of which is the Patient Leadership Council. And I'm very passionate about it. Because the Patient Leadership Council is the Arthritis Foundation's voice of the patient. It's really important for that voice to be heard in every race, gender, background, that there is. I'm really excited to be a part of this conversation today.

Rebecca:

Thank you for all that you do for us, Cristina. Not all listeners know I am Filipino, I'm Asian American. And so, talking about health disparity and equity and care is something I'm really passionate about. My mother has lupus and fibromyalgia.

I see how her views of health care... and how she was treated over the years or had a lack of health literacy when she first came to the United States in the '70s... or, you know, just really putting off her own health care because she was worried about taking care of her family and not necessarily herself. And I've learned, watching her over the years, so many things. Because she had to learn a lot of things the hard way, maybe my path was a little easier, right?

Cristina:

Yes, absolutely. My last name is Schaefer, but that is my married last name. I am Latina. There were times that it was uncomfortable, and it was difficult for me. Going to the pharmacy to pick up this painkiller, and I'm getting looks from the pharmacist and questions, because I'm sure there was some preconceived notion about me based on my race and my age. And "Why does this person need this extra strong pain medication?" So, there's definitely situations that take place that I think it's important for us to highlight and important for us to educate.

Rebecca:

Exactly. That's why I'm really glad to introduce our guest experts: Doctors Ashira Blazer and Michael Parks. They're going to help us understand a lot more about how health disparities can impact arthritis care and how patients can better advocate for themselves to get the best treatment possible.

Dr. Ashira Blazer is an assistant attending physician at the Hospital for Special Surgery and assistant professor of medicine at Weil Cornell Medical College. Before that, she was an assistant professor at the New York University School of Medicine in the division of rheumatology. Dr. Blazer specializes in the treatment of all rheumatic diseases, including inflammatory arthritis and systemic lupus erythematosis, particularly in patients of African ancestry.



Dr. Blazer has been recognized by the National Minority Quality Forum as a top 40 under 40 Leader in Minority Health. Thank you so much for joining us Dr. Blazer.

Dr. Ashira Blazer: Thank you for having me.

Cristina:

We also have with us today: Dr. Michael Parks. Dr. Parks is an associate attending at the Hospital for Special Surgery and associate professor of clinical orthopedic surgery at Weil Cornell College of Medicine in New York. He specializes in the surgical treatment of adults with arthritis requiring reconstructive procedures of the hip and knee. Dr. Parks has led a number of research projects at HSS, with a particular interest in socioeconomic and racial disparities in access to arthritis care and total joint replacement surgery.

In 2019, he was a recipient of the American Academy of Orthopedic Surgeons Diversity Award. He has served as president of the Orthopedic Research and Education Foundation and as past president of the New York State Society of Orthopedic Surgeons. Thank you so much for joining us today and welcome to the podcast.

Dr. Michael Parks:

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

Rebecca:

Dr. Parks, could you define for us what health disparities are for our listeners?

Dr. Parks:

There are lots of ways to define health care disparities. But among my favorite, the Institute of Medicine in 2003 had a report on disparities called "Unequal Treatment." And they defined disparities as racial or ethnic differences in the quality of health care that are not due to access-related factors or clinical needs, preferences or appropriateness of intervention. So, that leaves things like structural barriers, problems with access and other issues. Those are disparities.

But I also have another favorite definition from the World Health Organization. And they define disparities as differences in health, which are not only unnecessary and avoidable but in addition are considered unfair and unjust. So, whether or not a health difference is considered unfair depends on whether or not people choose the situation that resulted in poor health.

Dr. Blazer:



I think that's an excellent definition, and it really gets to the core that these are differences in outcomes that you see across populations due to differences in access, socioeconomic status, education; all of those structures that we know affect health and many other aspects of life in society.

And the other point I want to make is that when we talk about some of our systemic autoimmune diseases — lupus, rheumatoid arthritis — we're not just looking at disparities due to race; we also have disparities due to gender, because we know that these are diseases that more often affect women, who are traditionally marginalized in society.

Rebecca:

Yeah, that's another way to look at it, too. I mean, Cristina touched on... just women, in general, being looked upon perhaps differently. So, I'm curious though... This is a very unique topic to really specialize in. Can you share with us what led you to focus in a little bit more on health equity?

Dr. Parks:

It's really directed by two factors. One was my dad, who's no longer with us, but I watched him. He was an educated man. Had a master's degree from Columbia. He had access, he had insurance, and he had a son who's an orthopedic surgeon. He was an athletic person who played college football. And I watched him become progressively immobile.

He got to the point where he would crawl up the steps on his hands and knees. And I couldn't understand why he wouldn't access what I knew to be a very easily available solution to his pain. Also, I had patients that I would see who had the same problem, who wouldn't access what we could do for them.

Dr. Blazer:

Mine is also a family story. When I was in medical school, I became interested in immunology, and I was doing my musculoskeletal block. And around the time of finals, I called my cousin who didn't show up to our Thanksgiving dinner. And I asked her, you know, "What's going on?" And she says, "Oh, I've been sick." And so, she tells me her symptoms. And as she lists the symptoms, I'm reading them from my textbook.

I'm thinking to myself, "OK, I think this could be lupus," and I brought her to my then professor who got her in, got her diagnosis. And really, I was on this journey with her. Over the years, I've seen patients come in who were black and brown, and they had these very severe manifestations of lupus and a



very difficult time. And then I'd see my patients who were white come in, and they had a much nicer course, you know?

I would sit in these courses and various academic meetings, and people would say, "Oh, there's a genetic difference, there's a biologic difference. And you know, Hispanic people, there's some genetic dif..." Well, that doesn't make any sense. Hispanic people are from all over the world. Even African Americans, right? We have the oldest and most diverse genomes in the world. It doesn't make sense that there's some sort of gene that causes death by all causes, including lupus. So, it made me think, what are we missing in rheumatology?

Cristina:

How do these health disparities affect the quality of care and health care outcomes for arthritis patients?

Dr. Blazer:

In so many ways, really. We have to understand that these are chronic diseases that affect the totality of our patients' lives. All of the ways that disparities affect how well people can be educated, how well people can eat, how much they can access care. All of those things are going to converge on a patient with arthritis. Because that patient has to be able to afford medications, understand a very complex treatment plan, get to multiple doctor's appointments that might be farther away from their homes.

Dr. Parks:

We did a study here a few years ago where thousands of patients who had had total joint replacements, whether they were hips or knees, and we looked at their outcome versus what their race was and where they were from. Your ZIP code tells us a lot about where you're from. If you're from a rich neighborhood, a poor neighborhood, etcetera.

What we found was that, when we separated patients that were black versus white, the Black patients had more pain, poorer function. The Black patients didn't do as well in terms of how well they did postoperatively, even after they recovered. But then, when we laid on top where they were from, patients of color who were from poorer neighborhoods, as there was an increased amount of poverty, they also fared worse. So, this is sort of a multifactorial problem.

Dr. Blazer:



Our patients who are of minority groups come to us in worse condition, right? Delay in diagnosis is huge. Every disease state has a natural history. No one would expect someone with breast cancer who was diagnosed at stage one to do as well as someone who was diagnosed at stage four, right?

Just this way, arthritis has a natural history. You know, how long have you experienced this damage? How long has your lupus or rheumatoid arthritis been going on? How established is your disease? That influences what we can do for you when you do come to care. And often our black and brown patients bear the brunt of that delay.

Rebecca:

What about the dismissal of symptoms of pain or undertreatment of pain? Does that play a factor as well?

Dr. Blazer:

Absolutely. In order to be diagnosed with many of our diseases, someone has to believe you. That means you have to come into your doctor and say, "I don't feel well, I'm hurting," and your doctor has to say, "Maybe something more is going on," rather than, "I think you're just anxious." Or "You know, maybe if you just rested a little bit," right? Like someone has to say, "I am going to take the steps to get this work-up because I think there's something going on with you." We know that minorities tend not to get that benefit. We know that women tend not to get that benefit.

Dr. Parks:

We've done studies here, where we looked at patients and how their perception of their interaction with the physician was. And many African American patients who are women felt that their complaints were dismissed. So, we have to think about that. What are our implicit biases or explicit biases when we're dealing with patients? And hopefully check those at the door and meet the patients where they are so that we can again treat them equitably.

Dr. Blazer:

The other thing to think about: We think, OK, there's a bias in getting diagnosed. Every time you come in to see a physician, that physician has to believe you again and again and again and again, right? And so, one of the things I noticed with my cousin: She would have a flare-up, and her doctor might not believe that she had a flare-up that time, right? So, she would have to try to advocate and advocate and eventually she just got tired. It really requires a good relationship between the doctor and the patient in order to ensure that patients are heard, and doctors are doing their due diligence at every step of the way.



Dr. Parks:

Patients need to feel comfortable where they are and with whom they're being taken care of. There's a tremendous legacy of mistreatment of patients that we have to overcome historically in this country. Blood banks 50 years ago were separated by race. We all know about the Tuskegee experiment. We know about J. Marion Sims. They all play a role in perpetuating this disparity.

Rebecca:

Yeah, and I'm glad you mentioned that. How do you address the fact that in some cultures there is this mistrust of health care and systems and the people that are going to take care of you. If you're going to a doctor that doesn't look like you, is there a level of mistrust from the patient perspective?

I think about my mom, when the COVID vaccine came out... She's like, "I'm not sure what's in that yet. I need to make sure that people are OK when they do it. And I have lupus, and I don't know how it's gonna affect me." There's just this mistrust that I think some people have from that patient perspective. How do we move past that, and how do we better educate?

Dr. Parks:

I think that the one good thing that we can get from the COVID pandemic is: It has sort of brought to the forefront both these health care disparities. I try to open a dialogue and make the patient feel comfortable with their questions. And I also tell them, although they're coming to a scary place to see a surgeon in my case: They're going to decide what's best for them.

My role is to educate them, to tell them where I think they are, to give them my recommendations. And then I always tell them, "It's between you and that painful joint. It will often make you do something. I can't make you do anything, but I think that's gonna lead you forward."

Dr. Blazer:

I always say the first step in being trusted is being trustworthy. We all experience racism in our health care interactions every single day, right? Even Cristina's story, when you were talking about going in to get your medication, and the pharmacist is looking at you in a certain dismissive way, because, "What is this young Latina doing coming in for pain medicine," right?

It's hard to put a finger on because it can be so insidious that we can't say, "Hey, I'm experiencing racism." But people of color experience racism in their interactions. Even physicians of color. And you can't address something that you don't name; we have to say racism, right? We have to be able to say it out loud and try to do something about it. We have to listen to our patients and then not gaslight them and say, "OK, I understand, and I recognize that that is your lived experience."



PROMO:

Movement is the best medicine. But it can be hard when you hurt. Your Exercise Solution is a resource to help you create a customized physical activity routine based on your specific needs and abilities. Learn more at https://www.arthritis.org/health-wellness/healthy-living/physical-activity/getting-started/your-exercise-solution.

Cristina:

One thing that I think is common among communities of color are myths. Maybe myths in regard to what you may or may not be diagnosed with, what you are more susceptible to, or even your pain levels. Let's dispel some of them if you will.

Dr. Blazer:

I think one of the biggest myths is that if you have a systemic autoimmune disorder, particularly lupus, you can't get pregnant or you can't have a child. And I find very frequently that my patients either delayed their diagnosis or don't want to know or don't want to talk about it, because they were afraid that if they get diagnosed, they're not going to be able to have children. And, of course, these are women of childbearing age. Women with autoimmune conditions have many, many healthy babies.

So, if you are interested in having children, have that conversation with your rheumatologist very early, and make sure that you're in a place with your disease activity that you can have a healthy pregnancy, because that's something that we work towards.

Dr. Parks:

For me as a surgeon, I think that the myth is mostly that related to fear. It's just that patients will come in and they are fearful that they're going to, one: be offered an operation; and two: if they're going to have it, that they're going to lose their life or their limb or they're going to have some catastrophic outcome.

People from communities of color are so fearful. "Is it going to be a year before I recover? Am I going to be out of work for six months?" And so, these sort of myths about how this surgery that's done, particularly in the case of total knee replacement, about 400,000 to 500,000 times a year; and total hip replacement, 300,000 to 400,000 times a year... That it doesn't work or that they're gonna have a bad outcome. And that doesn't mean that everyone needs surgery, but they just ought to be aware of this option that's really effective.



Dr. Blazer:

A couple of others that I will add to that... One is that you can do either traditional Western medicine, or you can do alternative therapy. Many, many patients, especially with these confusing symptoms that sort of wax and wane... think, if I just fast for a little while, if I eat a vegan diet, if I exercise a certain way or if I pray a certain way: This autoimmune condition will just go away on its own.

Things like rheumatoid arthritis, lupus, where you get flare-ups, and then periods where you feel pretty good, people can get lulled into this sense of security that, you know, they can stop taking all medications or stop consulting with their physician and do just fine. And I think that that is so harmful, because what we want to do is prevent those flare-ups.

Every time you have a flare-up with your autoimmune condition, you have inflammation that can cause a scar and injury to your body. And people who have repeated episodes of this don't live as long and don't live as well. I try to impress upon my patients: Have your wellness practices. That doesn't negate the utility or need for taking some of these other medications or coming to see me.

I actually do work in West Africa on lupus, in Ghana, in Nigeria, and one of the things that people say to me all the time when they're first diagnosed is, "Is this a spiritual attack? Did somebody curse me?" You know, there are a lot of these ideas that you have this condition for some supernatural reason. And that actually carries a big stigma too, right? It's like, "Oh, I'm cursed, and I feel this way because..." And so, I spend a lot of time talking about just what this is and why it happens, situate this disorder in the physical body so that people don't carry that undue burden.

Cristina:

Some of our listeners may have never had a productive doctor-patient relationship because of biases in care. So, how can someone improve communication with their doctor? And how can they best advocate for ourselves during appointments?

Dr. Blazer:

I say don't take it on all by yourself. I think this also gets the idea that... Many people of color, many women of color, are used to taking everything on themselves, right? I'm the person who does it all: I take care of the children, I take care of the family, I'm nurturing everyone, and I don't fill my own cup.

If you're the one who's sick, it is very difficult to retain all of the information and make a plan. Bring a family member, bring a friend, get involved in a network of people who have lived this experience.



There are organizations like the Arthritis Foundation, the American College of Rheumatology... These are resources that you can use to foster your support and extend your reach.

Dr. Parks:

Talk to people, talk to your primary care doctor. Tell them, "I have this problem, who do you think would be good?" Find out who the people that are providing culturally competent care, who are going to make you feel comfortable and cared for. And to me, that's the most important step in establishing communication. And once you're there, you should feel free and comfortable asking questions and finding out the answers that you need so that you can go forward.

Dr. Blazer:

Don't settle for the first thing that you get. You know, I cannot tell you how many times patients are like, even my own cousin, "I went to this doctor. She wasn't great for me. But you know, I'm just gonna do what she says and then maybe it'll get better." No. If this is not the right doctor for you, it's not the right doctor for you. Go find another doctor. People in rural areas or areas where there aren't many rheumatologists or orthopedics may not have that option. But if you're in a major urban center, protect your energy, go find a doctor who's listening to you.

Dr. Parks:

Use your network. Ask: "Where am I gonna get the best care? Who's the best person to give it to me?" Seek them out, see if it works for you. I find that if you go to a low-volume center or someone that doesn't specialize in it and you have a bad outcome, that's just going to perpetuate the reason why we're here. "You know, they took care of me, and I didn't do so well." And so that just leads to a sort of self-fulfilling prophecy and the perpetuation of disparities. So, I think that we have to feel free to get another opinion and access the best care that's available to us.

Rebecca:

Always, always get another opinion. I am at the point where I've had so many surgeries that I do get two or three opinions every single time I'm told I have to have surgery, even if I liked the surgeon that I was planning to use to begin with.

A lot of times you see people saying in support groups, or online or in person, that, "All the doctors keep telling me that I have to lose weight, and that's the only solution for me." That's very frustrating for people to hear. How are you as a health care provider gonna guide me in that process?

Dr. Blazer:



A lot of this doesn't make sense, right? (laughs) Two-thirds of people in the U.S. are overweight or obese. They are not crippled. If this were only a problem of weight, then we would see so many more people suffering, right? It's another one of these things where you give a solution that either is not very feasible or will take an extremely long time.

Losing more than 10% of your body weight triggers a number of physiologic responses that make it difficult to lose even more, and also make it more likely that you'll gain. Also, we give things like steroids or people who get steroid-induced insulin resistance. We give insulin, right? So now you're fighting against medications and also your own body. There are lots of ways to live well at multiple weights. And so that is something that you should be hearing from your physician. And if you're not, you should think about finding another.

Dr. Parks:

One of the things that we do well here at Hospital for Special Surgery is not to just dismiss people about their weight. We have medical specialists in weight management. So, it's not just lose weight, it's we'll help you lose weight. And then, by the way, here's the treatment plan for your orthopedic malady; this is what we're going to do. This goes back to... You wanna go somewhere that you feel comfortable, that you feel that the doctor is going to partner with you and help you on this journey to wellness.

Dr. Blazer: For sure.

Rebecca:

So oftentimes, people with arthritis, and especially people of color, have other conditions along with the arthritis. So, having to juggle multiple specialists or multiple chronic diseases to manage is not easy to do financially, logistically and just in life in general.

Dr. Parks:

I see patients who come in often and they have pain. And so, they're like, "Oh, my knee's killing me, I can't walk, I need to fix it." "Oh, by the way, you have diabetes. Have you seen a doctor?" "No, I haven't." And the diabetes is way out of control, and they don't understand that that problem's gonna kill them. Their painful knee is gonna make life not as pleasant, but it's not going to kill them.

I'm gonna take care of that knee, but I'm gonna also encourage them to prioritize these painful conditions. And every time, the heart disease, the hypertension, that's out of control, the diabetes that's out of control, every time that's gonna beat my knee or issues with mobility. Now, I let them



know that I'm gonna be there to help them when they resolve those issues, but I can't just wear blinders.

Dr. Blazer:

Patients of color come with a ton of comorbidities because the health care system, education system, nutrition system does not serve communities of color well. A lot of the comorbidities that we see also impact arthritis and arthritis care. Diabetes, heart disease and hypertension. And so, I think this is where wellness practices come in.

How should you eat to not develop that problem in the first place? How should you be meditating to take care of your mental health? How should you be exercising to make sure that your physical and mental is doing really well?

Cristina:

When is it time to seek out another doctor? Maybe not even a second opinion at that point, but just a different doctor? And what qualities should they be looking for?

Dr. Blazer:

I encourage second opinions in general. Think about the kinds of things that are important to you. Do you need a physician who's culturally congruent with you? Do you need a physician who matches your gender or gender identity? Do you need a physician who trains in a certain place?

And then also, I think this is a good role for physician extenders. You know, a lot of our black and brown patients don't have the luxury of being able to seek culturally congruent physicians because we know that the physician workforce is very ethnically homogenous and greatly white.

However, our allied health professionals are much, much more diverse. And so perhaps you should be seen at a practice that engages pharmacists, social workers, nurses, NPs in the point of care. Because even if you're not getting as much face time with the physician to get that explanation, you're able to then engage one of these other professionals who can meet some of your needs.

Dr. Parks:

I just think at the point that you feel that you're not comfortable asking questions and you feel dismissed, then, in my opinion, the relationship is over. You should always be able to ask questions and to feel comfortable that you are heard in the practice.

Cristina:



What about the emotional effects of having arthritis? How can patients take steps to better their mental health?

Dr. Parks:

There's a talk I used to give when I would go to senior centers or churches, and the last slide was a set of stairs. And it said, "Climbing a set of stairs shouldn't be as hard as climbing a mountain." And I think the first thing that people need to realize is that it's not necessarily a natural part of aging to be immobile and to be in pain.

So, I think, again... Empowering patients to be a part of this decision-making process of "How do we resolve this?" How do we improve that pain? How do we get them more mobile? And I think that that is a first step toward addressing the mental health and being willing to consider what your options are.

Dr. Blazer:

Mental health is health. People have flare-ups when they have stress. So, you know, not taking care of your mental health is the same thing as not taking care of your physical health. And I think when we talk about black and brown communities, many of us have these stigmas against taking care of mental health, going to see a therapist, taking a medication if you need to take a medication. Let all that go. No one would ever say, "Oh, I have diabetes, but if I take insulin, then I'm weak." Right?

Rebecca:

Right.

Dr. Blazer:

The other thing is: Don't suffer in silence. Many of our patients, really many of us in general, think that we should have to endure. We should be resilient; we should be strong. There's a trope: the strong Black woman, right? The strong Black woman is tired, OK? (laughter) Like, she's not doing well. She's not taking care of herself. Don't be her. Get the resources you need to get.

Cristina:

Absolutely. The COVID pandemic has brought some of these things to light, and I think with mental health, that's probably one of the top issues that's been been brought to people's mind, and people are seeking outside help if they need it.

Dr. Blazer:



A lot of my patients bring up that they're having a little bit of anxiety or depression. I say to them, "Oh, when I have anxiety, depression, I go and see my therapist." And so, then me saying, as a physician, "This is something that you can take care of, and this is my experience with it," that makes them feel freer to talk to me about it. That's how we break down stigma.

Rebecca:

Yeah, normalizing it. But like you just said, I'm tired. (laughter) I can't do everything and be everything to everyone y'all, and so I'm gonna take a break.

PROMO:

The Arthritis Foundation's Walk to Cure Arthritis is back in person! Together, we're raising money for better treatments and a cure for the nearly 60 million Americans with arthritis. Help Rock the Walk. Sign up at https://www.arthritis.org/events/wtca.

Rebecca:

We have a listener segment in the podcast where we post some questions on social media and see how people respond. So, we asked, "How has your ethnicity, gender identity or sexual orientation been a barrier to accessing arthritis care?"

One person commented: "What does any of that have to do with arthritis? It's about your insurance and the type of insurance you have or don't have, how many rheumatologists you have." Then somebody replied to that comment and said, "The human factor. Discussing how a medical professional has their personal biases that impact their work with a patient and may not realize they're doing that." What are your thoughts on that debate?

Dr. Parks:

We're all human. We all have our implicit biases. I mean, that comes without a degree or profession. So, just like any other profession or group of people, we're plagued by those same biases. Hopefully, as professionals, we can check those at the door, but we have to have conversations that are open like this so that we discuss them and bring them forth, to the forefront. Because if we tuck them away, then we're just gonna allow them to fester and to perpetuate.

So, it's not so much about your race, your gender, your sexual orientation, but it's about: Do you as a human feel comfortable connecting with the other human in the room? Do you feel comfortable with the care they're providing?

Dr. Blazer:



Certain groups of people were made to feel less human. Some of that was actually written into our laws and constitution. When we think about people who are from traditionally marginalized groups, whether that's race or gender or gender identity or sexual orientation, literally someone is coming into this interaction and saying, "Do you recognize my humanity?" If I am going to be able to support your life, I have to be able to recognize your lived experience.

So, if I'm your physician and I can't be bothered to use your preferred pronouns, what does that say about what I think about your life experience? We have to remember that 95+% of the care that you will receive will come from you. If you are not empowered by me to care for yourself, you're not going to do well. So, it has everything to do with arthritis and health.

Rebecca:

Another person on Instagram, Linda, said that when she had shoulder replacement surgery, she faced disparity when it came to receiving adequate treatment for her pain. "This is a common trend that Black people will face in receiving health care services with the myth that we have a higher tolerance for pain." What do you say to that, Dr. Parks?

Dr. Parks:

This goes back to J. Marion Sims, who experimented on enslaved women without anesthesia because women of color didn't have pain. I think that you have to make sure that you have that connection, and you have to be able to advocate for yourself, you know: "I'm having pain, I have this problem." Here at HSS, one of the benefits is that we have so many specialty services. So, pain management is going to be done by someone who only does pain; someone who specializes in that and hopefully get away from some of the bias.

Dr. Blazer:

There's a long living history of this, and it's like we've been playing this racist game of telephone for hundreds of years. The knowledge that we have comes from somewhere. Someone had a question, and they did the research, and then that research got incorporated in medical journals, then medical journals got incorporated into textbooks, and that gets taught to our budding physicians, right?

We are going to have to look at the way that we think about and teach about race and change the perpetuation of bias, this being one of them. We need to make sure our doctors don't think that way actively with re-education.

Rebecca:



Thank you. Carrie on Facebook said that it's a battle every time her husband's employer changes insurance companies because they're constantly having to fight to prove that they need the medications that are prescribed. Do you see this often in practice?

Dr. Blazer:

Literally every day. (laughter) It is not just her husband that's fighting, I'm fighting, too. It's a huge problem. This is where we need to advocate for policy changes, right? I think it's so important for patients to live with their voices and say, "We are suffering with the American public, we pay our taxes, and we are suffering in this way." It is also important for physicians to join hands with those patients and advocate to change the system.

Dr. Parks:

I just want to echo that. It's so important. Advocacy is such an important part to allow us to care for our patients and it goes beyond medicine.

Rebecca:

Absolutely. And at the Arthritis Foundation, advocacy is a huge thing that we do, and I know Cristina and I are both very vocal and have been on the Hill.

Cristina:

It's really important to kind of tune in and see what is happening because it could affect my care and my friends' and family's care at any point.

Rebecca:

Advocacy is a huge piece of what do at the Arthritis Foundation to raise that patient voice to have better access to treatment and care.

PROMO:

Take the INSIGHTS survey to change the future of arthritis today. Your responses will help shape tools, resources and programming for arthritis patients and their families, as well as a powerful advocacy and research agenda that fights for you. Make change happen today by visiting <u>https://www.arthritis.org/liveyes/insights</u>.

Rebecca:

Dr. Parks, Dr. Blazer, Cristina, this has been an amazing conversation. Would you like to share your top three takeaways from this conversation?



Dr. Blazer:

The top one is we are all human and being able to recognize the humanity of someone is required for being able to provide care. My second takeaway will be advocacy. Self-advocacy as well as national advocacy to make sure that we're able to combat some of these disparities. And my last takeaway will be mental health. Mental health is physical health, and we have to take care of the whole person.

Rebecca: Love it. Dr. Parks?

Dr. Parks:

Well, I think my first takeaway is that we all deserve equal care. So, wherever you go, you should feel comfortable and that you are in the hands of someone that shares the paradigm that they're going to do the best to take care of you and provide you that care. The second thing is, I think that you need to realize that you have to speak up, you have to be a part of that. And the third thing is: Climbing a set of stairs shouldn't be as hard as climbing a mountain.

You should realize that if you have a problem, whatever it is, whether it's a mental health problem at your mountain, or whether it's an arthritic condition, you need to seek help and hopefully find a provider that will partner with you to come to a resolution that is acceptable for you.

Rebecca:

Those are some great takeaways. Cristina, do you have anything you want to add?

Cristina:

When you're seeing a new physician for the first time, we mentioned bringing a friend or family member; don't put it all on yourself. I think that's really important for a patient, especially if they're seeing a new physician.

It's important to ask questions and advocate for yourself. If a doctor is telling you something that doesn't sound right or telling you something that you don't agree with, it's OK to ask those questions. Then the last thing was, just if you feel like you're not being heard, if you feel that this is just not the right situation, it is OK to seek a second opinion or find a new physician.

Rebecca:

Thank you all for joining me in this conversation. One of the reasons I'm so proud to be part of the Arthritis Foundation is one, our advocacy efforts in making sure that people have access to care for



all the care that they need for their arthritis. The Foundation is working really hard on several different issues related to reforming step therapy, as well as supporting some bipartisan efforts to cap Medicare Part D out-of-pocket costs. We know that out-of-pocket costs can also be very prohibitive to accessing care.

We're also working on a bill to help ensure copay assistance counts towards out-of-pocket costs by passing the Help Copays Act. These are three things that you as a patient with arthritis or a caregiver or a loved one can also advocate for. So, if you visit our website, you can find out more information on how you can take action and send information to your members of Congress.

If you are having any questions related to access and treatment for your arthritis, if there's anything that you need or have questions for, we have a helpline that you can call, and you can also access it online. Our helpline is 800-283-7800. Thank you all again for this discussion. And have a great day.

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