

### Transcript Details

This is a transcript of an educational program. Details about the program and additional media formats for the program are accessible by visiting: <https://reachmd.com/programs/project-oncology/addressing-health-disparities-for-blackafrican-american-patients-with-multiple-myeloma-topic-1-patient-experiences-how-to-improve-diversity-in-clinical-trials/13212/>

### ReachMD

www.reachmd.com  
info@reachmd.com  
(866) 423-7849

---

Addressing Health Disparities for Black/African American Patients with Multiple Myeloma, Topic 1: Patient Experiences & How to Improve Diversity in Clinical Trials

### Announcer:

You're listening to *Project Oncology* on ReachMD. This episode is sponsored by Amgen Oncology. On today's program, we will take you to a special Grand Rounds Educational Program featuring an expert panel addressing health disparities for black or African American patients with multiple myeloma. In this episode, the panel focuses on patient experience and how to improve diversity and clinical trials, moderating the discussion is Dr. Ian McFadden, Medical Director of Oncology Medical Affairs at Amgen.

### Dr. McFadden:

Alright, thank you everyone for joining today. I'm Ian McFadden. It's my privilege to introduce our panel.

Firstly, I'd like to introduce Mrs. Lenora Johnson. Last year, Lenora was diagnosed with multiple myeloma. Presently she travels 250 miles each way, three weeks out of every month to obtain her care as part of a clinical trial. And I just want to relate to everybody listening, and you'll hear it, Lenora has such a generosity of spirit. She expressed to me that her main goal is to help someone else who might be in a situation like hers. So, thank you, and welcome Lenora.

Next, it's my privilege to introduce Kimberly Boshell. Kimberly is a registered nurse with over 20 years experience in oncology nursing. She spent the last two years of that in the Blood and Marrow Transplantation Center at the University of Alabama at Birmingham, or UAB, where she is also a clinical research coordinator. Thank you, Kimberly, and welcome.

And thirdly for our panel, we have a man who will need no introduction for many of us who work on multiple myeloma; Dr. Luciano Costa, who's an Associate Professor of Medicine at UAB, an active physician, and clinical trial investigator. Among his many employments, Dr. Costa is the Medical Director of the Cancer Center Clinical Trials office at UAB. Thanks very much for being with us, Dr. Costa.

So, I'd like to start with you, Lenora. If you could think back to last year before you knew you had multiple myeloma, what did you know about multiple myeloma as a disease and maybe you could tell us a little bit about how you found out that you had multiple myeloma?

### Lenora:

Thank you. It's a privilege and an opportunity to share with you my story, my diagnosis, as well as my treatments. I like to say that my story may not be the norm, you may have seen other things in your practice, but I'd just like to share that with you. I always went for my annual checkups and I always made sure that I had my mammogram, I checked my blood sugar, and I was diagnosed with osteoporosis, so I made sure I followed those. I thought about it, I had not had my eyes checked in over a year and I knew that my eye doctor had retired. I went to the optometrist, and they checked my eyes but as she began to look at my eyes, she said, "I see blood behind your retina," and I said, "Blood?" And she said, "Yes," she said, "It doesn't look like diabetes," but she said, "I do see blood behind your retina and I'm gonna have to send you to the ophthalmologist." And so, she made an appointment for the next day, and I went to see the ophthalmologist. They checked my eyes, but they went a step further by having my blood drawn. He said, I think he said, my blood count was 3. And so, he said that, "You go to the hospital right now, and you don't drive, and you make sure someone takes you there." And so, I stayed there for three days, and they gave me seven pints of blood and told me that I was anemic and to go back to the clinic to be followed there. But in the meantime, they began to monitor my blood and, they said, "Well, you're not getting any better," so they hospitalized me again. I stayed there seven days that time and they did all kinds of tests; x-rays, panels, and they checked my kidneys and I mean it was just a whole lot. And finally, they called in the oncologist and she said that, "I believe that I'm almost sure that you have multiple myeloma," and, you know, my first impression, my first thought about it was that, "Well, Lord, I am no

better than anybody else and if this is what your will is, you gonna have to work it out 'cause I don't know what to do." As I said in the beginning, my story may not be the norm. The average person that I know of, in fact just from talking to people, they wait until they're sick, really, really sick but as I said, mine may not be the norm because I was already researching in the medical community 'cause I'd been keeping up with all my appointments and everything.

**Dr. McFadden:**

I really appreciate you providing perspective about your diagnosis. Thank goodness you got your diagnosis when you did.

I do also wanna turn to Dr. Costa on this, as well, though. You know, Lenora had an interesting point about how patients sometimes think they have other symptoms of something else going on and they wait a long time or maybe don't like to go to the doctor. I'm wondering in your day-to-day practice, you know, how are you aware of differences in how patients present with the disease and is there any to that to different cultures?

**Dr. Costa:**

Thanks, Ian, that's, you know, that's a great question, and I just wish you could spend the rest of the hour listening to Mrs. Johnson because Myeloma itself is a very, you know, diverse disease in how it presents. I mean for many patients they're completely fine, it's just an abnormality on bloodwork. Many patients, however, present with worse circumstances, renal dysfunction, you know, anemia or sometimes painful, and very serious bones lesions, sometimes with fractures.<sup>1</sup> So that's, you know, part of the disease. There's not much that can be done about it. But, unfortunately, we see people will sometimes be, you know, have anemia for months and be sent from one doctor to a doctor having all sorts of procedures before somebody connects the dots and think about myeloma. The same thing about kidney dysfunction. I've had both having chronic kidney disease for months before somebody found out it was actually multiple myeloma causing kidney damage.

And yes, I think that first interaction with the healthcare system sometimes determines your, determines your outcome. And individuals who have less, you know, doesn't have the access to a tertiary facility or specialized care, sometimes have their care negatively affected by not, you know, getting to the right resource or not having access to someone who could've made that connection. It can be very, very disappointing.

**Dr. McFadden:**

Sure. Would you say that's maybe one of the main reasons why we see this on average African American patients are later to more modern standards of care and it may not receive them?

**Dr. Costa:**

Absolutely. We see, you know, undoubtedly, we see that, and I think the data, there is hard data that shows that, you know, black patients in general take longer to start treatment.<sup>2</sup> And we see that in our practice, as well. The diversity that does exist is not only racial but is educational and it is socioeconomic. And in our country, unfortunately, those things are interconnected. And often times, you know, the patients with less educational attainment, with less income, don't have the best health literacy are also disproportionately black, and they end up suffering from all those imperfections of our healthcare system.

**Dr. McFadden:**

Now, Kimberly, I would like to get your perspective, as well. What are some of the things that you do, in particular in your role as a nurse, to ensure, you know, equal quality of care and access to treatment for all of your patients?

**Kimberly:**

Well, I mean, of course you wanna treat all patients the same. That is, that is a given. But sometimes you have to use different resources because our patients require different resources. Depending on where they're coming from, if they're coming from a rural area, I'll spend more time and resources as far as education and as far as what the study is asking, what we're requiring, what their outcomes are gonna be. As far as a nurse, it's a lot of educating for me. And they're not the only ones on this journey; they're taking this journey with their family, their extended family, there's church family that'll come with them. So, it's a journey and it's also to make sure that your patients know that they're not alone; that you're accessible, they can call you at any moment and you're there to answer any questions big or small.

**Dr. McFadden:**

I think that's a really powerful thing that you do and inside for us, you know, maybe there's an opportunity to provide better resources, not just for patients but for caregivers, as well to have those conversations with doctors and with the healthcare system to really understand, you know, where they are, what the disease is, what the options are and how to navigate.

Speaking of that, I actually do wanna turn back to you, Lenora. You know, thinking back, you mentioned that you did take up a clinical

trial at UAB. And so, one other thing you touched on a couple of times here is you say you and people you know don't always trust the doctor right away, but in this case, you know, you wanted to be in a clinical trial and you're aware of the history of clinical trials. I'm wondering how trust in the system and trust in clinical trials factored into decision-making?

**Lenora:**

It really, you know, the thing about it is with life, life changes and what a clinical trial was fifty years ago doesn't mean that it's that today, and you have to have that mindset to know is that things do change. As an example, I said to you the other day my father, who lived to be 91 years old, he wanted certain kinds of physicians and he only wanted those physicians. With me, it's totally different. I'm looking, I'm always open to know that time changes, life changes, situation changes, things change! And you have to understand that. So, that's basically the way I look at it. I just trust 'em. I, you know, I trust them. If they have the credentials, they've been through the study, that's what's needed.

**Dr. McFadden:**

I appreciate that. You mentioned something interesting as well, that I think we're gonna end up coming back to, and that is, you know, sometimes people want to see themselves in the healthcare system, they wanna see a particular kind of doctor, and I think we're gonna touch on that in a moment.

I do wanna turn this as well to Dr. Costa. You know, I know you have an interesting take on the so-called trust issue. I wonder if you could speak a little bit to that?

**Dr. Costa:**

Absolutely, and thanks for bringing this up, and I'll try to answer this and stay composed. You know, what we just heard from Mrs. Johnson, that she articulated very well, is it's really a very powerful message of forgiveness. It's just too humble to put on those words. But that's what we see, you know, black patients have been taken advantage of, they have been abused, they have been ignored. The medical field has neglected them historically, and what does Mrs. Johnson have to tell us? That I'm ready to put this in the past and trust because I wanna help others. And that is a very powerful statement, that we do not, that we shall not, we do not take lightly.

Offentimes when the conversation goes on about including minorities in clinical trials and including black patients in clinical trials, as soon as that gets brought up, the issue of trust comes up. And yes, you know, black patients have all the reasons to mistrust or distrust the healthcare system. You know, we think we're in a better place than we were in the 40s or in the 60s, but we still have to prove that, right? We think we are, we have to, to prove that. We have to own this as a society, not, you know, not say, "OK, you know, the problem is black patients don't trust doctors, don't trust the medical research." So you know, they have, you know, black patients have done way more than their fair share to advance this country, to advance medical research, and to advance equality. You know, the rest of us have to do our part.

**Dr. McFadden:**

I'm glad that you said that, because one thing I wanted to show here is Dr. Costa, you're kind of known for doing your part now. So I just wanted to get into, you know, to what do you attribute your success? You know, what are some of the practices that you've done well to step up?

**Dr. Costa:**

Yeah, thanks Ian. I think, you know, this is really by no means my success. And I'll tell you I think what is by far the most important thing is where we are is location. We have the privilege of being on a state that is 30% black.<sup>3</sup> We are the privilege of being on a city that is a majority black. And that give us this terrific opportunity to have a relatively high enrollment of black patients into our clinical trials. And so, if you're doing trials in an area that don't have a significant, high proportion of black patients, it's gonna be very difficult to have a high enrollment. I don't wanna, you know, take credit away from our institution and therefore that, you know, Kimberly and others in our team put, but the most important thing is where we are. And I think whatever time the discussion comes about minority, the words that come are underrepresented, underserved, you know, is a message of need of what we don't have, and I think we need to start thinking of diversity, and in particular in black participation, in myeloma trials. We need to start thinking of this as being an asset and I think we need to have the incentives in place and the right mindset to think of working with minority patients as being just that, being a privilege.

**Dr. McFadden:**

That's actually a point that I wanna get back to. When we look at the statistic of, you know, national clinical trials pooled together is still only 5% or 6% of participation of African American.<sup>4</sup> We have to do something with that privilege. It's, you know, many of those trials are done at major metropolitan sites that do have populations that could be served. So, I think there is something to be done. You know, you mentioned you didn't wanna look past the efforts of Kimberly and others and neither do I, so I do wanna turn this to Kimberly quickly.

**Kimberly:**

Well, here at U of A, I mean, we're a medical team but we also put ourselves in our patient's care. We're present. We're upfront. We're available when we're needed. We stop, we listen. To being personally involved with our patients and practice communication, that is the number one thing to have here and that's how our team here at UAB, we do that very well.

**Dr. McFadden:**

It sounds like it, I know we've talked before about, you know, access to resources and maybe you could tell us a little bit more about how you facilitate that for patients.

**Kimberly:**

Upon first meeting our patients, Dr. Costa has already spoke to them and then I, kind of walk in behind him with my little southern accent and, they kind of know that, OK. So we just kind of sit down and we talk and most patients we go from the start of the study, through transplants, to what our expectations are at the end. So, it kind of helps alleviate some of the unknowns, some of the fears. And then from there, we talk about what what resources do we need to get you back here to get this medication that is so expensive that you have to take three weeks a month. So, for me, my main goal is to take Dr. Costa's idea, and take Mrs. Lenora and I kind of put it together. So as a nurse, it's finding the resources. I may not know the answer, but finding the answer for our patients.

**Dr. McFadden:**

Much, much appreciated. I'm thankful that you do that and so I'm sure all of your patients are, as well.

In that spirit, on behalf of my colleagues, I just wanna express our deep and sincere appreciation for everything that all of you are doing, you know, in terms of efforts to improve the lives of African American patients with multiple myeloma and that will conclude our program for today.

Thank you very much again, everybody for attending.

**Announcer:**

You've been listening to *Project Oncology* on ReachMD. This episode was sponsored by Amgen Oncology. For access to this and other episodes from this special Grand Rounds Educational Program addressing health disparities for African American patients with multiple myeloma, visit [reachmd.com/ProjectOncology](https://reachmd.com/ProjectOncology). This is ReachMD. Be part of the knowledge.

**References:**

1. American Cancer Society. <https://www.cancer.org/cancer/multiple-myeloma/detection-diagnosis-staging/signs-symptoms.html>. Accessed January 27, 2022.
2. The ASCO Post. <https://ascopost.com/news/october-2019/study-finds-disparities-in-treatment-of-african-american-and-hispanic-patients-with-multiple-myeloma>. Accessed January 27, 2022.
3. U.S. Census Bureau. U.S. Census Bureau Quick Facts. <https://www.census.gov/quickfacts/fact/table/AL/RHI225219>. Accessed April 12, 2022.
4. International Myeloma Foundation. <https://www.myeloma.org/diversity/how-myeloma-different-african-americans>. Accessed January 27, 2022.

USA-171-81711 04/22