FAQs on Health Equities in Multiple Myeloma

January 24, 2024

Transcript

Mary DeRome (MMRF): Welcome, everyone, and thank you for joining us for today's session on frequently asked questions on health equities in multiple myeloma. I'm Mary DeRome, senior director of medical communications and education at the Multiple Myeloma Research Foundation. Today, I am joined by Dr Craig Cole from Michigan State University in East Lansing, Michigan, Amy Pierre from Memorial Sloan Kettering Cancer Center in Montvale, New Jersey, and patient Beverly Kerr, a myeloma patient living in Salisbury, North Carolina. They have agreed to answer some of the frequently asked questions we receive from patients and caregivers about health equity in the treatment of multiple myeloma.

So let's start first by talking about disparities. Health equity for multiple myeloma patients has been a topic of discussion, recently, at both annual oncology meetings like the American Society of Clinical Oncology, or ASCO, and the American Society of Hematology, or ASH. Dr Cole, what can you tell us about the role of race in multiple myeloma?

Craig Cole, MD: Thank you so much, Mary and the MMRF, for having this meeting. Talking about this, getting a message of empowerment and hope out to patients and the myeloma community is so important to eliminating these disparities, and so thank you for that.

What is the interplay between race and myeloma? Of course, I'm going to say it's complex. It's an interplay between the biologic differences between races with multiple myeloma.

But also, there is a significant interplay between other social determinants of care, an interplay between social economic status and insurance clinical status. This is apparent when patients present, how they present, who they present to, where they present, and what type of access these patients have. There are also psychological and environmental issues, which have a smaller interplay. Additionally, there are cultural issues that interplay in race and myeloma and the delivery of care.

Some of the obvious biologic things are that myeloma is twice as common in people of African descent, not only just African Americans in United States, but people of African descent around the world. One of the first papers, written in Jamaica, back in the 1960s, showed that there's a higher incidence among

Black myeloma patients compared to White patients in Jamaica. For men, it's about 16 per 100,000 for Black men, and for all races combined, it's more like 8.8 per 100,000. For Black men and Black women, they have double the incidence of other races, while people of Asian and Native American backgrounds have a much lower incidence of myeloma.

That's also reflected in the precursor disease. Monoclonal gammopathy of undetermined significance (MGUS) is more common in Black people than in White people, and probably the prevalence of MGUS is much higher than we think. The original studies that looked at MGUS were done in Olmstead County, starting in the 1960s, and Olmstead County in Minnesota doesn't have a lot of Black people in it. There was an abstract at the ASH meeting, this past year in 2023, looking at a small country in southern Africa that found the incidence of MGUS to be 13%. That is much higher than what we think of in the United States.

Black patients present four years younger than their Caucasian counterparts; they present with more anemia, higher calcium levels, and more kidney insufficiency which are myeloma defining events. Not as many bone fractures, because people of African descent have a higher bone density than their Caucasian counterparts.

Furthermore, Black people are less likely to have the high-risk cytogenetic lesions that we associate with myeloma. The deletion of the 17th chromosome 4;14 and amplifications of chromosome 1 less likely to be found in Black patients. And again, at this last ASH meeting, I kind of called into question the idea of 11;14 being more common. There's one study that said the 11;14 was more common in Black patients. Other studies haven't found that to be necessarily true. One abstract at ASH showed White patients have a higher mutational burden in their myeloma cells than Black patients. Another study done through the Emory Group found that there were different mutations in Black patients compared to White patients.

When you look at some of the other social determinants of care, it kind of comes down to access. It takes longer for Black patients, women, and Hispanic patients to get diagnosed with their disease. They're less likely to have access to what used to be called the four Ts and now I call the Q3T quads: four-drug induction therapy, clinical trials, transplant, and T-cell redirection therapy. Again, less likely in Black and Hispanic patients than in Caucasian patients.

We do know, and several studies have shown that, with equal access to the care and the clinical trials, that people of African descent have the same, if not better, survival than their Caucasian counterparts. So, that's it in a little nutshell.

Mary DeRome (MMRF): A nutshell, perfect. So, Amy, do you have thoughts on what can be done in the myeloma community to help overcome racial disparities and improve patient outcomes?

Amy Pierre RN, MSN, ANP-BC: Sure. Thank you so much for giving me the opportunity to be a part of such an important discussion. It's so great to be here with the three of you and the online community. That is a very important question, Mary.

There are so many racial disparities and inequities that we currently see, that Dr Cole touched upon, and a lot of that is due to longstanding ramifications of structural or systemic racism that affect specifically what he talked about in terms of social determinants of health.

Once the myeloma community has a deeper understanding of these underlying factors, they can take strategic steps to dismantle it. Structural racism is a form of racism that is pervasively and deeply imbedded, and is found throughout systems, laws, written or unwritten policies, in trench practices, and perpetuates the widespread unfair treatment of people of color.

A specific component of structural racism that affects the myeloma community, for example, is residential segregation. A lot of Black myeloma patients live in segregated communities and obtain most of their oncology care in a community setting and may not have access to all those wonderful therapies that Dr Cole spoke about. Those novel therapeutics sometimes can be only primarily prescribed and are given by specialized academic institutions, particularly those with clinical trials.

Another component is financial practices. Black myeloma patients have a higher cost of care, probably related to their underlying higher comorbid conditions or other health concerns like kidney disease. They have a higher cost of care and statistically have higher numbers of patients who are lower income and have lack of insurance or under-insurance, which leads to issues with access to care. There's also data aggregation, which is a lack of reporting diversity or lack of diversity, at all, in clinical trials.

As Dr Cole spoke about, we have an increased disease burden, in the Black population, of myeloma. Black patients make up more than 20% of myeloma patients, but they make up only less than 5% of patients in clinical trials. When we look at myeloma trials performed in the US between the years of 2007 to 2014, the racial, ethnic composition of those trials was only reported in 40% of those clinical trials. So we don't even know what we don't even know.

Understanding the systemic pieces to these inequities shows that several steps can be taken to undermine these inequities, including partnering with Black communities, continuing to spread knowledge and awareness of myeloma at events such as this, providing resources, decreasing financial and logistic barriers such as transportation, and developing diversity plans to improve representation of Black patients in myeloma trials. Also, understanding our own conscious bias and our unconscious bias contributing to these inequalities in care.

Mary DeRome (MMRF): That's great synopsis from the two of you about what the issues are and how we might be able to solve them. It's really so exciting to see all of these discussions taking place at the major medical meetings now, right? These things have been going on for a long, long time, but we're finally talking about them and trying to address them. These problems are not going to go away overnight, but like you mentioned, you have to recognize them and then try to determine how to solve these problems. And then, hopefully we'll all get there, to where we need to be in the near future, right?

Now we're going to turn to Beverly. Beverly, thank you so much for being here with us today to tell us your story. As I mentioned to you before we started the program, this is the first time we've had a patient who has experienced these inequities, to talk about your experience, and explain how you tried to help yourself through these things. So, you had delays in getting your multiple myeloma diagnosed, which is not uncommon. And can you tell us about the journey and how you finally came to suggest that you might have multiple myeloma, to your doctor?

Beverly Kerr: Thank you, again, for the opportunity to be able to talk about multiple myeloma. It's not just myeloma. I think there are many disease process inequities that happen to people. My background is in health education, so, I'm going to discuss this not just for me as a person, but as what I've experienced as a patient, a living human being, because it was rough.

I started feeling poorly I would say around 2000. I started feeling achy and my hands and my back, especially in my back. I never really had back issues, so I was, like, "What is going on with my back?" I go to the doctor regularly. That's the other thing that a lot of people don't do; I go to all my annual visits. I realized how important that is due to my background in health education.

Now, understand the majority of people in the population, especially in our community, do not have that kind of relationship. I worked in targeted infant mortality and a lot of women felt like their prenatal visit was their annual visit. When we don't understand our doctors, and even in our community we may interpret differently. The way we talk to our doctors and the way we deal with our physicians is a barrier for us in care. I kind of get personal with my doctors, because I have the background. I think that I've got to be respectful and honest in that sense, that maybe I wasn't giving the right explanation. I couldn't give her a good idea about what was going on with me, because a lot of people have back pain, a lot of people have headaches.

And I had comorbidities. I had obesity; I was smoking at the time. I had a Arnold-Chiari malformation diagnosis in 2000, so I attributed a lot of what was going on with me to a prior disease process, as well. So let me just be fair with that. You also must be responsible for your total care. When you don't have that or no one's taught you about that, that is what Amy was saying about systemic racism. We don't like to go to the doctor. So, when I started this process of getting worse and worse, I had a stroke in February of 2000. That was at the beginning of COVID-19, so I said "I don't know what's going on with me."

I thought maybe something happened to me because I had gotten COVID-19, and maybe it was coming from that. Or because my husband started off with a bad respiratory infection in 2019. Things had happened to many of my family members, through this period of time, so I'm thinking, "What is going on?" And then when I started getting worse and worse, my numbers began to change.

In November, I had my records, and November 30th of 2022, my whole chemistry started to change. And that's when I got scared, because the doctor sent me a notice and said to me, "Beverly, are you bleeding anywhere?" And I was, like, "What do you mean by that?"

I love MyChart (an electronic health record) and I'm glad we have that kind of electronic system. That's what we need to teach people right now: how to go to your MyChart and watch your numbers yourself. Teach them the basic chemistry of your blood, and if you see something hopping off, don't let somebody tell you it's not okay.

It was a medical provider (MP); she wasn't my doctor. Let me be clear about that, too. She was not a medical doctor. She was qualified, by all means, but she didn't know. She just didn't know, because it's not typical.

Of course, myeloma, Black female, we didn't know at the time. I'd never heard of it myself, so how could I be sensitive to something I had never heard of myself. I have to be fair. So, she asked me if I was bleeding, and I sent her back a message, "Where do you think I'm bleeding at?" We're going back and forth on our call.

My sister and I, we both have back issues and things. I thought about my father; he was a scientist. I'm very clinical when I do things. I think laboratory. I'm very, "I got to figure this out."

My sister called me one day and she said, "Beverly, we have a relative that sounds like she has what you have. She's my mother's cousin's daughter. "She has multiple myeloma." And so, I said, "I don't have no cancer, no myeloma," I'm thinking, "I'm too – I don't do anything for that." I also heard that there was lupus; that my grandmother had lupus, and we had a relative pass away from lupus. I was thinking with those two diseases in my family, I went to my doctor and told him, "Hey, test me for lupus and multiple myeloma," and that was in May of 2023. Those years, 2000, 2020, years that I'm having a lot of different issues, going back and forth to emergency rooms at different times, and just all kinds of things. I'm just going downhill. I feel myself going downhill.

My sedentary rate came back at 86, from the test the doctor performed. She wasn't alarmed by that. But I was, because I looked on Google. Google's my doctor. Google said if it's 86 to 100, I could have some kind of sensitivity in my blood, or arthritis. My dad had osteoarthritis. So, I said, "Okay, I got arthritis."

I wasn't thinking cancer. That was not even close to what I was thinking about I had. But my inflammation marker was off the chart.

Dr Cole, you said MGUS. I'm glad that I'm getting to express myself, because I never heard about MGUS until now. That means something on the clinical level, but to me and you, say you were my doctor, I'm MGUS, you say that to me. I'm going to have to go home and read about that. And most people that are on this webinar would have to go back and say, "What was he talking about MGUS?" What specifically, did he say?

And when we finish, I'd like for you to tell them what MGUS is. Because if it is the beginning phases, then that's where we need to start, in terms of explaining MGUS. Tell these people; diagnose people with at least MGUS. So we could start the process, even tracking data and information. Because this is what I do, and I'm also a grant writer.

My research on Google said immune disorders and certain things can come from having an 86 sedentary rate, and that's really when I became aggressive with everybody. I said, "Okay, now what's going on with me? Inflammation is not normal in the human body. Don't tell me I have inflammation. Don't tell me I have fibromyalgia. I already had all that, you know. I'm talking I already have 20 diagnoses. None of that is adding up to what this is."

I just noticed looking at my charts today, that my C protein marker was elevated on March 29 2023. Back then, I got mad at my doctors; everybody made me mad. My husband and I both got really sick, one night, and we both went to the emergency room. I went to another emergency room. I went to another hospital. Because I said, "I am not crazy now. I'm sick. My blood pressure's all off the chart.

My body's hurting, my feet," I mean, just everything, my digestive, I had classic multiple myeloma symptoms, once I knew what I had. And so I'm said, "Everything is off." We went to the emergency room, I was having pain in my right side, really bad, that night I went to the emergency room on April 17th. They gave me a computerized axial tomography (CAT) scan of my abdomen that night. Believe it or not, they never gave me any results from that scan on April 17th.

Two days later, I was still in pain, so I called my family doctor, and I went back in. And I said, "I was at the hospital," she said, "No, no, no, you were at the hospital – " and it wasn't my normal person; it was another lady named Katie. And she said, "Beverly – " and she looks scared. She literally looks scared, because they know who I am.

Katie's nice, but I could tell she was concerned; something was bothering her. So, I said, "Katie," I said, "What's going on?" and she said, "Beverly, did they tell you what's going on with you, at the emergency room visit at the other hospital?" I said, "No, they didn't tell me anything. I have my results and it said abdomen pain." She said, "No, they found that you have lytic changes in your bones. They found that you have two abdominal tumors."

I asked, "What does that mean? I've never heard 'lytic changes,' I've never heard. I didn't know I had any abdominal things going on." And she said, "Bev, I can't say you have cancer, but your numbers and everything is not looking good, so you can't leave the office today." I just sat there. But believe it or not, I wasn't afraid. I just knew I had to keep fighting to find out really what was wrong with me. And she said, "Well, we're going to send you right now today to a CAT scan; get you scanned again and see what we've got going on." We got the CAT scan, we ran new bloodwork, and she said, "Is there anything I can do for you?" after I waited half a day to get the appointment, they wouldn't let me leave the office.

Get the appointment, go get the scan done, and I said to her, I said, "Please, send me to the best cancer doctor that is around here," and she said, "I know one." And so, by April 20th, I was sitting in Dr Brinkley's office, whom I love dearly. And his team, they are so good. That whole Wallace Cancer Institute in Salisbury, North Carolina, is right up there with Mayo, as far as I'm concerned.

Mary DeRome (MMRF): It is great that you found a good team. That's so important.

Beverly Kerr: Really, they treat me well. They've treated me well as a patient, but that doesn't apply to everybody. I always have to put disclaimers in there, because I'm also probably a little bit more knowledgeable about the medical stuff, so we talk differently. So, in that aspect, I have to talk from an advocate standpoint, not from a patient, because I'm not a typical patient. Dr Cole knows that, and Amy knows that as well. Most people don't present like they have enough knowledge to know how to go back and look at all the results. I know how to analyze my numbers; I know how to look at things and see what they are. I know how to fight without fighting, or being too emotional or arrogant about my situation.

I also have to respect that they are the professionals, and they know what they're talking about, as well, and they're fighting this fight for us every day, as well.

With that C protein up high and all the results came together, by May 8th, Dr Brinkley had me sitting and getting chemotherapy. I started with bortezomib. I think it was daratumumab, bortezomib, and something else. I was getting zoledronic acid.

It's the first cocktail they give you to get started. And they worked. May 8th, when that stuff hit my blood, I went straight into shock. My body reacted so well, and I'm going to say first you think it's bad, but it reacted so well. He had to send me across the street to the big hospital, and I ended up in ICU for a few days, because I couldn't walk.

I was slowly going downhill. By the time I got to the Cancer Institute, from that point, once I knew something was wrong with me, everything started collapsing. My body start reacting. It was just bad. So, I was in the hospital May 8th. May, June, July, it was killing me. The cancer was so quick and violent in terms of what was going on, but I was getting better, boom, better, boom, better. I didn't like the neuropathy and the pain in my feet. That was the worst thing that I'm experiencing now from lenalidomide, and from some of the different drugs that I've had to take.

Overall, right now, see how clear I am? I haven't had chemo since September. We started my harvest with Dr Ailawadhi at Mayo Clinic. My harvest went well. I only got 6,000 stem cells and my buddy got 13,000. We were laughing about that this morning and, I said, "Man, you're going get more transplants than me." Because, we do know there's a chance for relapse and different things like that.

Overall, I must say to you that if all of the things that Dr Cole talked about and Amy talked about, we deal with it from a standpoint of, yes, racism is stress. When most diseases start, it's stress related, your stress, your genetics, your food.

I've had to change, not even change, just recognize that certain foods we eat cause this. Everything has a cause and effect. And if you have the right doctor, he knows how to educate you.

Let me tell you what my team looks like. You can get this clearly. Because there's a lot of people helping me. I have a dietician. I have a health coach. That's through GI Thrive. That happened because my husband works for Walmart and they have a program called Centers of Excellence. I'm able to go there, not because I can afford it. It's because Walmart has this wonderful program that you go to; you can go to these awesome facilities for treatment.

Typically, people don't know about what their companies provide. Yes, get the cancer. When you get to a certain age, you need to be buying cancer policies. You need to have certain things in place, just because that's what could happen. Especially, as Dr Cole was saying about environmental issues. We live in poor environmental conditions. From structural racism or any other issue, we're unhealthy in our country in terms of just about every marker. We have all this technology, but we're so slow about using the technology to heal ourselves.

So, April 20th, sitting in there, first round of chemo, but here I am today with you, clear-minded, able to get in this fight with you. There are lot of the organizations and places I work with. NC Counts Coalition, I worked with them during COVID-19, events across North Carolina. We've started a network that I can plug in information like this about health equities.

We dealt with COVID-19. That's why I thought my back was hurt, because we were setting up tents and stuff everywhere. And I told my boss, Melissa, I said, "Melissa, you killed me." I thought my back had gone out, because of the work we were doing.

I just had surgery December 5th. They couldn't do my transplant until I got rid of the tumors. I had eight tumors, not two.

Mary DeRome (MMRF): Eight? And what kind of tumors were they?

Beverly Kerr: They were fibroids. Dr Cole, what do they call them? I can't remember.

Craig Cole, MD: Plasmacytoma?

Beverly Kerr: No, they were fibroids, uterine fibroids because I had a hysterectomy. Anyway, I'm doing well from that, I just had my last visit from my surgeon, Dr Amy Wallace. You should see my scar, it looks beautiful. I don't even feel like I had surgery.

As I said, Dr Sikander Ailawadhi, Virgnia Lesperance, they're getting me ready for transplant.

Julie in human resources (HR) at Walmart keeps making sure my husband has a job, because you have to think about FMLA. My team is extensive.

What I see for the future of this, Mary and all of you, is similar to we did for targeted infant mortality. We need to have programs in communities that know about all of these things and go door-to-door. You know, basically say, "Hey, this is the big disease, this is diabetes or myeloma". We need people. We call it, at NC Counts, boots on the ground. We need boots on the ground to go in these communities and educate, with people who look like you, and understand you.

I wouldn't even say who looks like you always; it's who has the passion to be able to get that information to you. Because my doctors don't look like me, but they love me, and they care about me. Once I learned how to talk to them and communicate with them, they don't look at that. It's about quality of life, quality of services, quality of time, getting good listening skills and things like that. At Moss Counseling, my counselor, Beverly Moss, and my psychiatrist and people like that, are people who listen to you because you're going through something.

Your family and your caregivers and everybody who's involved as a team, as a part of your care, they don't know. They want to help you, but you must have people who understand your process. And we need to really make it so that the disease itself is not scary. You know, we're so fearful in our community of everything, because we've been abused. And we don't want to be used. That's why we don't go to clinical trials, because we remember syphilis. Everybody goes back to the syphilis trials and what happened. Those are real things that happened to our people in our community.

People need to understand this happens, and even though it could be 300 years later, we still feel it, because nobody acknowledges that this happens. It doesn't mean it is happening today. If you don't tell somebody you're sorry, and really mean it, they never forget. You need to prove it.

And with health, you need to prove to me, "Okay, Dr Brinkley, this product is going to work, but what if it doesn't work for me? What are we going to do?" Do not throw me away. You're going to find the next treatment. We found things that put me in the hospital every week and then we had to pull back from it.

I'm going get my second bortezomib shot on Friday, and I'll be in the hospital the next day. But he had to push it, to kill as much of the cancer as possible.

And they had to explain that to me, "No, we're not trying to kill you, Beverly, but these are the steps, here are the processes. We're dealing with your symptoms, we're getting you as clean as possible, and as quickly as possible, we need to get you to stem cell transplant." That was the discussion from the beginning. That's what I heard. And that was my experience. That was my cancer. My oncologist said, "This disease requires this, this, and this, and that's what you're going to have to do."

So I just settled down and went for the ride, and it was what it was. And that's why I'm sitting here today, and I am extremely grateful to the entire team, especially my husband. Because thank God for him, and the job that he has. He's also my caregiver. His employer let him off; he goes to all my appointments, and he's been able to be with me through all of that. This is not a typical story. I want to make sure that's clear. If there's not a person like a caregiver, we have to have places where they can find caregivers that can go with you.

The hospital requires that you have somebody with you through stem cell therapy. We need resources that ask, "Do you need somebody?" We can start with something through a health department for caregivers to be able to go in and go with people through these major chronic illnesses. You need help, that's the thing, financially, mentally. You have to look at a holistic approach with multiple myeloma and moving forward.

I think so much wonderful work has already been done. I met somebody, a few days ago, that's had it since 2012. Her story scared me half the death, because she's relapsed so many times, but she's living. And she said, "Beverly, don't be stressed." She said, "I'm going to tell you right now, do whatever it is you need to do to keep your stress level under control and your diet." Kevin, another patient was saying to me about the stem cell transplant, "Beverly, make sure you walk, and you exercise." Like, you need a pre-stem cell bootcamp team to talk with you. I'm telling you, because, see, I know how to listen and learn. I think that's why I'm doing so well.

My team is phenomenal. My home team is phenomenal. As far as North Carolina, there's so much research that goes on in this state. It's huge in academics and education. But I don't think the average daily person, before they come into a traumatic illness or a chronic illness, they're just not taking good care of themselves.

So, at the end of my conversation with you, the factors I think that we have to look at are high stress levels, lifestyle changes, diet changes, adequate sleep and rest, financial distress, lack of access, improved access to healthcare, ability to get insurance, and mental health support overall. And family counselling, if necessary, because any health marker can improve with everyone working on the same thing.

Mary, I thank you. Amy, I thank you for your part. And Dr Cole being at that table and fighting that fight. I go to conferences, and I know how they work, and it takes doctors like you saying, "Hey, I'm going to fight this fight, we're going to get on this and we're going to deal with this and make this a lifetime thing." And Dr Ailawadhi told me from day one, when I went in his office, , "I am the myeloma doctor."

Mary DeRome (MMRF): He is, he's great, Dr Ailawadhi.

Craig Cole, MD: He is very good.

Beverly Kerr: I feel like the queen of myeloma, right now. We're going to heal some people; we're going to get some things done; we're going to make a difference in the world. And you only can do it one person at a time. This is going to go out to the world, but if nobody listens, still, we are going to find a way to get this information to the masses. I’ve got my people in North Carolina, and I sent out a message to everybody, "Listen to this, today." Thank you. Thank you for the opportunity to talk.

Mary DeRome (MMRF): We're very happy to have you. That was really an inspiring story. So, you were diagnosed in 2023, but you started feeling poorly in 2020, right?

Beverly Kerr: My actual diagnosis probably was April 23rd, almost a year-to-date, in April of 2023.

Mary DeRome (MMRF): Let's move on and talk about some additional things that are of interest here. Dr Cole, Beverly mentioned that she had a cousin who had multiple myeloma. Can you talk to us about what role genetic inheritance plays in multiple myeloma? And what is the risk for African American individuals?

Craig Cole, MD: Beverly, you've stolen so much thunder of what I was going to say and suggest, that I'm a little cloudy, now.

Beverly Kerr: No, we need you. We need you.

Craig Cole, MD: Thank you so much. And to answer your question, Mary, since the 1990s, we knew that people of African descent had a closer hereditary risk of myeloma than White people. There's a study that looked at other blood cancers. Myeloma has a greater heredity pattern for Black people than in White people, for not just myeloma but all blood cancers. There was a study that was done fairly recently, that looked at both molecular and genetic components, and also looked at epidemiology. In that study, they found the odds ratio of myeloma being associated with family history was 20.9 for Black patients and just 2.0 for White patients.

Mary DeRome (MMRF): Wow.

Craig Cole, MD: There is a closer hereditary pattern for myeloma being hereditary. Usually, we look at that hereditary pattern as being myeloma and people inheriting the MGUS risk. That is why it's important to know about MGUS. But the bottom line is that we need more studies. The study that I had mentioned was published in 2016, but we need more studies with Black patients in them, in order to really get that pattern seen.

One study that's looking at that is the Promise Study which is enrolling any Black patient over the age of 50 years or anybody with a primary family member with myeloma. As soon as I turned 50 and I was eligible for it. I went right out and signed up for the Promise Study.

And that is the way we're going to figure it out. Number one question I get is, "Why does this affect Black people more than White people and other ethnicities?" We don't know, but things like the Promise Study and being involved in clinical trials will get us there.

Mary DeRome (MMRF): Yes, yes. It'll also ensure that the findings of clinical trials are more applicable to every patient. When we've achieved the goal of having 20% of patients enrolled in clinical trials who are of African American descent, that will be so helpful, in all of these things.

So, Amy, what could the myeloma patients who are listening today tell their relatives about the possible risk of myeloma? What to look out for, whether they should mention it to their healthcare providers, do you recommend that Black patients with multiple myeloma suggest that their close relatives be screened to look for multiple myeloma precursor conditions like MGUS or smoldering myeloma?

I think that the Promise Study is a great way to do that, actually.

Amy Pierre RN, MSN, ANP-BC: Yes, and I'm glad you introduced that, Dr Cole, because the Promise Study is a great way to understand and be a little bit more proactive about understanding your risk. The statistics show that myeloma is rare, but of course if you have a first degree relative with myeloma or a related condition, your risk increases. And multiple myeloma is the most common blood cancer for Black Americans. Therefore, if they have a first-degree relative with myeloma, their risk of developing myeloma is two- to four-fold higher.

I would say for all the patients who are listening today, please feel empowered to advocate for yourself and for your loved ones, and discuss your risks and concerns with your healthcare providers. If you have a family history of a blood cancer, talk to your healthcare provider about this and what it means for you, and also your family members. If you are a patient of color, your risk is even greater, and you can participate in clinical trials that allow for free screening for myeloma or its precursor condition, MGUS, such as the Promise Study.

As Dr Cole said, the Promise Study screens patients who are actually age 30 or older, who are African American, and/or people of any race who have a parent or a sibling or a child with myeloma or another blood cancer or another related condition. They're also enrolling people who are 18 and older who have a strong family history of a blood cancer, so, two are more first- and second-degree relatives. So, there are ways for you to take the steps and get screened, if you are truly interested in understanding what your risk is.

In terms of what to look for, the two most common presenting physical symptoms of myeloma are fatigue and back pain. I'm sure all of us on this call right now have had fatigue and back pain, it's very vague. So, I think the most important thing you can do is just be verbal when things are not right in your body, and of course take steps to screen yourself.

Mary DeRome (MMRF): Right. I personally have submitted blood samples to the Promise Study because my mom had multiple myeloma. And I have encouraged people that I know, who have first-degree relatives, to contribute their samples to the Promise Study, as well. I think this is going to be really very useful when they gather all the patients. I'm not sure what their final number is now. I think it was originally 30,000 people they wanted to screen, or something like that. They might've lowered it, I'm not really sure. Anyway, I think it's a great thing.

Beverly, is this information new to you, that family history of multiple myeloma increases your risk? Have you discussed your diagnosis with other family members and whether they might be at increased risk for this disease?

Beverly Kerr: Absolutely. And not only just for me; I talk about it all the time.

I've had workshops and seminars where I'm a speaker or whatever, I always talk about myeloma. When I talk to people, they look scared. They're, like, "Nobody wants to hear to C-word." They're almost, like, "I don't want to get diagnosed."

But I tell them, "If you find out the earlier – " and as with any other disorder, the earlier you find out about it, you have a higher chance to survive it. And survive well. Because I think the treatments are there for myeloma and a lot has been done. I remember when we used to hear a lot of years ago about bone marrow transplants. Now they say stem cell transplant. I didn't even associate this correctly when initially diagnosed because stem cell is a new technology, a new word.

We also must remember, as educators, we keep changing the words. We go for minority, then we go to black, indigenous and other people of color (BIPOC). I mean, every week we're changing terminology. And because a flip of a switch of a word changes the way we could have conversations in our community. I think language is a key. If our physicians and our nurse practitioners and our educators, the way we speak is how people respond. I could say breast cancer, and we all know Susan G. Komen. We know there's a correlation with the foundation.

I have a secondary thing that I'm going through right now with breast cancer; I'm going get all kinds of help. But with myeloma, everybody's, like, "Well, what is that?"

For example, transportation money, there is no source for that. That's why I want to push our foundation. That place is where our money can work. We can start these ‘pots of resources’. Even if I have to write the grant, for crying out loud, that way I know people are getting transportation. That's a huge thing, getting into the office because every week, with cancer, you're going to the doctor.

My copay is $75.00 every time I go, so it's expensive to be sick. But what do we do to stay well? Inform our family members, let them know what's going on, and it's still a lead-a-horse-to-water-but-you-can't-make-them-drink thing. You can educate and you can say, "Hey, this is familial," but if they don't listen, that's what makes it tough. This Promise Study can get us, like Amy was saying, a screening.

Actually, Amy, I had fatigue so bad. I could be on this program right now and just fall asleep. That's how bad it was for me; that's where I was.

It's like a battery, my charger would go down. So, you're right, fatigue and that back pain, stay on them, until your blood changes. I kept track of my medical records on MyChart. You can see in my bloodwork numbers on Nov 30, 2022, when I went to the doctor for a visit. From the last visit to that one, it was that much of a change. So, I could say from November, almost a year, November 20, 2021 I was normal, by November 30, 2022, my numbers were high.

So, it was a year. But I never heard, honestly, Dr Cole, I never heard MGUS, at all. I still don't hear it. The Promise Study means something to me today, from listening to you. I had no idea, you know, what to call it, even.

Mary DeRome (MMRF): We do have some resources at the MMRF that explains what MGUS actually is. This is part of our patient toolkit, so it's like a brochure. You can actually go onto the website, you can read it on the website, you can download it from the website, you can send in a form and we can send you a toolkit that has all the booklets in there that talk about multiple myeloma. So that might be something that some people are interested in.

Let's move on, now, to talk a little bit about disparities in access to care. Data shows that Black myeloma patients are substantially less likely to be referred for autologous stem cell transplant, which is what you were talking about, Beverly. And that is an obvious contributor to poorer outcomes for African American patients. So, Dr Cole, what is driving that substandard care?

Craig Cole, MD: Yes, that's a good question. That's a really good question. A lot of it is definitely the disparities and the access that we talk about. Because the transplants are done at academic centers, primarily, it requires a referral from a community physician to an academic center, which limits access. A study done a few years ago showed that a lot of physician-bias plays a role in pursuing transplantation.

When you get Black patients and patients of color to the transplant center, they're just as likely to want to get a transplant as anybody else. A lot of physicians and patients may say, "I'm too this, I'm too that to get a transplant. I have too many comorbidities." I once caught, a few years ago, a fellow saying, "Well, that patient really shouldn't be referred to a transplant center, because of such-and-such." And I said, "That's not your call to say if a patient is eligible or not eligible for a transplant. They need to talk to the transplant center in order to do that."

When you talk about inherent bias, and sometimes obvious bias, especially between decision- makers, they end up being gatekeepers for these transplants.

If that gatekeeper thinks, "Gosh, I don't want to refer my patient out, because I'm worried about another person taking care of them," then that puts up a barrier we need to overcome. One way to overcome that barrier is getting second opinions, when patients have myeloma, and talking to the transplant center directly.

If your doctor says, "Well, I don't think you're eligible," then you say, "Okay, let me talk to the transplant doctors and see if they think I'm eligible."

Mary DeRome (MMRF): Right, so these are times that patients really have to become their own advocates. To get the care that they need, they need to make sure that they're taking the correct steps and talking to the right people, and making sure that they get what they need. Beverly, you talked about being a little forceful when you're talking to your care teams and just trying to get what you want, or what you think you need, right? These things are very important for patients.

So, Amy, is there anything that we can tell myeloma patients who are listening today, to empower them to advocate for their care, to help ensure that they have access to these standard treatments like transplant, so they can achieve their best possible outcome?

Amy Pierre RN, MSN, ANP-BC: Favorite question. Yes, absolutely. So, despite Black Americans with myeloma having all those inequities that Dr Cole talked about, a higher risk of delay in diagnosis, a higher risk of delay in starting their first treatment, less likely to receive those novel therapeutics, transplants, and trial participation, there's so much data, as you said, to support that if Black Americans with myeloma receive equal access to care, their outcomes are equal, if not better, than their counterparts. I always tell my patients that the best type of healthcare is the type where patients are actively participating in their plan of care. They're asking questions; they're clarifying important concepts; they're proposing things.

The conversation with your healthcare provider should be a two-way street, right? You shouldn't be sitting there mute and your provider's just talking to you. Always ask your provider why they're recommending the treatment they're recommending. Why is it individualized for you? What are the alternatives? And what are the pros and cons? These are fair questions to ask and it only inspires a dynamic conversation and knowledge sharing for both you and the provider.

Mary DeRome (MMRF): Perfect. That is great, great advice.

Beverly, you have a transplant coming up in a few weeks, and we all hope that everything goes very smoothly for you in your transplant. At what point in your treatment discussion was transplant discussed?

Beverly Kerr: I have to say, I remember Doreen telling me right away. Part of the whole treatment plan was, boom, "This is step one, step two, step three, May 8th, this is where you're going to start. We're going to see how quickly we can get these cancer cells under control with the treatments that are available" They focused straight on just getting these cells down. I had 100% infiltration.

By October 2nd, I was at Mayo Clinic talking to Dr Ailawadhi and he was explaining to me with my transplant team what could be done. There is a lot of testing on your organs and there are a lot of things that have to happen to make sure that you're strong enough; your body is healthy enough. Some tests do come back as you may not qualify; you may not be well enough to receive transplant.

But like Dr Cole also said, don't tell me I can't have it.

Send me to the transplant center, because that's what they did. They never told me there's a chance you will not qualify. They did tell me to stop smoking. If you are a smoker, stop. Because that'll take you out of qualification, for the most part. There are a lot of things you can't do. Surgery, smoking, there are certain things you just have to not do, so your treatment can be better. Quit as soon as possible, as quickly as you can. We're talking about doing cessation classes to help people because there are many pollutants and everything if you smoke. If you can get it out of your body, the faster your treatments may work.

So that's why all these tests and the clinical trials and all the things that Dr Cole was talking about, that Amy's talking about, in terms of access and all of these things, being active participants in your care, it's a two-, three-, four-, five-way street.

Right now, I think just from the conversations that we've had today, I see a roadmap already in place for care for multiple myeloma.

I think we really have come far. What was missing was having somebody like me at the table who can talk about all the great stuff you guys are already doing, Amy and Dr Cole. You didn't just start working at this, and I realize that, but I'm very new to this, you know, in terms of care. I met a few people that have been in this, they're not even at transplant level, yet. That’s how quickly I have come through. There's a lot of things that you have to be cognizant of when it comes to your care and quality of care for each individual.

It depends what communities you come from. Your doctor may not be getting enough CME credits or your nurses. There's a big picture. One thing that I learned about this, working with Yvette and how Yvette questioned me and, she was so good at listening to me, to get me to come to talk today. Most people say, "I'm not going to get on the camera and talk about this disease," or anything else, for that matter. But when someone comes to you saying, "Hey, we're going to do something about this, there is something that needs to be done, things that we can get done," that's what makes it a lot easier.

Mary DeRome (MMRF): Yes, agreed. That's great. Speaking of care, access to clinical trials is another barrier resulting in outcome disparities for Black myeloma patients. Dr Cole, can you provide some insights on this and thoughts on how we can address this question. This is very close to home for the MMRF, because this is one of the main things that we're working on going forward. Making sure that, for the trials that we work on, there is adequate representation of all the real-world multiple myeloma patients, which means at least 20% of African American patients.

Craig Cole, MD: Yes, and just like you said, Mary, the MMRF's really at the forefront of this. We're one of the first organizations that really embrace the absolute need and the priority to enroll diverse populations in clinical trials. If you only enroll one population in a clinical trial, you don't know if it works for everyone. The number of Black people that have myeloma of the overall myeloma population, is about 20%. But historically, and even recent history the number of Black patients involved in clinical trials for FDA drugs for people in the United States only enrolled, like Amy had mentioned, 4.5% to 5%.

We're doing better with that, we're approaching enrolling patients in the United States at more like 15%. We're getting better. But really to understand this disease and a way to understand how all these drugs work, we need to be even better. Remember, there's biologic differences between Black patients, Hispanic patients, and patients of Asian descent, with this disease. And to know how well these drugs work, what the side effects of these drugs are, who it works best for, who it does not work best for, we need to enroll diverse populations in these clinical trials. And the FDA saw this clearly, a couple years ago, and put out a requirement for clinical trials moving forward in the United States. Cancer clinical trials moving forward in the United States need to have a plan to enroll diverse populations in clinical trials.

Now what we need to do is have investigators enroll and go out and seek out diverse populations. In my prior life, I could enroll the same patient in three clinical trials during their course of treatment. That helped that patient, but did it help the myeloma community? Not so much. Our mission now is to go to the communities, to talk about clinical trials, to offer clinical trials, for patients to always think, "Do MILs before a clinical trial." Because clinical trials just aren't for the end of advanced myeloma or newly diagnosed; it's the entire continuum.

And just like Beverly said, what I do is exactly what she said.

When I sit down with a newly diagnosed patient or a second opinion of someone I just met, I always say clinical trials and stem cell transplant. I mention the Q3Ts every time, so it doesn't come as a surprise when I say, "I think now it's time to do the transplant." I mentioned that on day one, so it's not a surprise when it comes up. When someone has relapsed or when they're in maintenance therapy and I say, "Well, we have a clinical trial," it doesn't come as a surprise. It is part of every conversation that we have, and that's what's important for patients, getting that second opinion.

There are so many clinical trials out there for myeloma; we are so blessed to have so many clinical trials. It is now time to be involved in those clinical trials, so we know that these drugs work for everybody. That's how you find the cure to this disease.

Mary DeRome (MMRF): Absolutely. And, it's vital for people to enroll in clinical trials, because the more data and the more samples you can collect from a representative population of patients, the faster we are going to be able to get to a cure for multiple myeloma. And certainly, be able to personalize people's treatments based on their clinical characteristics, their genomic characteristics You know in the MMRF, we have our Compass Study, which you are very well acquainted with, Dr Cole, and we enrolled something along the lines of 17% African Americans in that study.

That was not a study that was testing drugs; it was a registry study where we were collecting data from patients and samples from patients. That study enrolled, from 2011 to 2015, we enrolled over 1,000 patients in that study, and we followed them over the course of 8 years. We're just finishing our last follow-ups now from 2015 to 2023, and we have so much data in our databanks from all these patients who donated their time and their samples to this study. This data is used all the time by many, many large studies looking at the genomics of multiple myeloma and trying to figure out who the correct patients are to receive which therapies, and which ones are going to work the best for that patient.

And that's where the field has to go. Personalized medicine is very important in myeloma, because everybody's myeloma is so different. The more data we collect, the more samples we collect, the closer we're going to get to that. And that's what I think we are all working towards, which is great.

So, Amy, in your experience, are there implicit provider biases around the participation of Black patients in clinical trials, such as Black patients not being interested in clinical trials or not being compliant, that need to be addressed? And is there a difference between academic cancer treatment centers and community practices, in that regard?

Amy Pierre RN, MSN, ANP-BC: For the first part of your question about implicit provider bias, unfortunately, there is. There was a study that came out of ASH, in 2002, that was exploring the factors influencing underrepresented racial and ethnic groups to participate in myeloma clinical trials, and the results were quite astounding. The study interviewed hematologists and patients. The most common underlying factor to influence determination of enrollment in trial was trust. There was also acknowledgement of implicit bias in terms of hematologists saying they expect a patient of color to automatically turn the trial down.

They feel a Black patient is less likely to fit their typical paradigm of what a typical clinical trial patient is. Or a Black patient is of lower socioeconomic status, so they may not be adhering to the requirements of the trial. These are, unfortunately, real words and real feelings coming from providers. So implicit bias is most certainly playing a role in the underrepresentation of diverse myeloma patients and trials, as well as access to trials. And then, in terms of there being a difference between academic and community practices, I think academic practices have an easier time enrolling patients, given the depth and breadth of resources they have available.

That includes clinical trial coordinators, clinical trial nurses, clinical trial MPs. Academic centers traditionally have more trials available for patients compared to community practices. These factors matter, when most myeloma patients of color are being treated in the community and not necessarily having access to these academic centers, because they're so far away from them and where they work.

Mary DeRome (MMRF): That's where the specialists are located. We always talk about the fact that it's really important for myeloma patients especially, because it's such a complex disease, to really engage with a myeloma specialist as soon as possible, because that will help the outcome.

Amy Pierre RN, MSN, ANP-BC: And it's important to acknowledge what a myeloma specialist is, because some patients are in a community practice and they think they're seeing a myeloma specialist, whereas, that is just an oncologist who's seeing all blood cancers. And they see 12 or 15 myeloma patients in 2 years. It's really important to understand the level of volume of myeloma patients that providers see, to see if they're truly a myeloma specialist.

Craig Cole, MD: That's a fair question. I get that question all the time "How many myeloma patients do you see?"

And thank goodness I can't count that high off the top of my head, thank goodness. But also, if you ask me about breast cancer, I am clueless. I know nothing about breast cancer. My only gig is myeloma. And the other thing about academic centers, these days with telehealth, and even the technology we're using right now, we have access to patients around the country.

I have a patient I do a second opinion on that lives in South Carolina. I have a patient in Honolulu, Hawaii, and one in New York City that I give second opinions on. I talk about local clinical trials and access. And getting those second opinions not only gives your doctor information, but it empowers you, because you're hearing, once again, you're hearing from a different perspective about myeloma, about MGUS, about the treatment options. That gives you more power to talk to your primary hematologist at home, who may not see as much myeloma as a myeloma specialist, but that helps everybody.

I told my mom when she had hypertension, "Get a second opinion about your blood pressure," to hear it again, because the only thing that happens if you get a second opinion is good things.

Mary DeRome (MMRF): Great. Excellent.

Beverly Kerr: Mary, if I could say one more thing, bringing this all together, that I have, as a patient, being able to use telehealth is great. I've been able to use that a lot. Thank you both for talking about both of those issues. I think we hit on some great things. We need another session.

Mary DeRome (MMRF): Well, we're not done. We can just keep talking. This is such an important conversation, I don't want to cut anything short.

Beverly Kerr: There are several things that I've heard today, as a patient, that I think are so promising. Number one, Amy, that we've been talking about it the academic portion as opposed to community practice. That's another area I think we must understand, people think their regular regional hospital, that's where their professional is. They don't understand that, when I say I'm going to the Mayo Clinic, I'm going to the people who know about my disease. They're studying it.

If you don't teach people the levels of care, the majority of the population, when someone has cancer they'll go to the first oncologist, next oncologist, and next oncologist, until they die. But if somebody doesn't say, "Well, you can go to the Mayo Clinic or you can go to the cancer center at the University of Michigan or you can go somewhere else." They do not know if they're not exposed to the levels of care. Some of this also has to come from conversation and exposure in your community about levels of care. Even when you're saying academic and community, that means something to me. But to a layperson, academic means what? What does that mean?

We're teaching. There has to be another level of teaching about, or even when you're living, when you're about to get an apartment in a community, or understanding, "Well, how far away is the doctor's office? How many doctors do you have in your community?" There are higher levels where the incomes are higher, you're going have better quality care at hospitals, and it shouldn't be that way. You have to look at the reality of the situation. And Amy, you guys are hitting on that in such a way, I think it's just awesome. Understanding oncologist, what is an oncologist?

I didn't even know what an oncologist did until I got cancer. I really understand the role of my oncologist, now. I went to an obstetrician/ gynecologist (OB/GYN), for example, for the tumors. They sent me there first. He said, "Bev, I'm not qualified." I thought was awesome. I love him for saying that. He was honest. He said, 'Uh-uh, what you got going on, I’m going to find somebody." He said, "If they go in and you got more cancer, they can clean that up. Plus, they can deal with what you got going on. For me to do it and hurt you would be wrong."

So, he sent me and thank goodness. I'm here. I'm right here in front of you. I'm proof positive going to transplant, because she did her job so well. And I haven't had any upticks in my cancer because she knew what she was doing when she went inside my body. At Dr Brinkley's office, I said, "Well, you know, the old saying is, 'They open you up, you die."' You get cancer; you have surgery; it is a myth, but in our community, you've heard, "Well, they had cancer and they had surgery and they died, like, a year later."

Some things have to do with superstitions and things like that. I can admit that I was afraid. And I did ask. I asked Doreen, and she said, "Bev, no, that's a myth." I said, "Okay," because I didn't want to have surgery, knowing I have cancer in my blood. Some of the things that I didn't think I would have to be open to, I had to be open to such as some of the things I had been previously told were wrong. So, I just keep surviving every day and saying, "Okay, knowing this information, check that off, it worked."

Also, there are issues with age. Most of the people that I know that now that have myeloma are in their 60s and 70s.

Mary DeRome (MMRF): Yes, this is a disease of older people, for sure.

Beverly Kerr: Right. My godmother, her two sisters in New York City, they passed from myeloma. They were in their 70s.

When they told me, I said, "What? I have what?" I'm thinking, "That's an older people cancer." I didn't think about it for me.

Mary DeRome (MMRF): Yes, I think the average age of diagnosis, it's younger for African American patients by about five years or so, right? Something like that, right?

Craig Cole, MD: Yes.

Mary DeRome (MMRF): I think overall 68 or 69 years old is the average age of onset for myeloma, but it's younger for African American patients.

Beverly Kerr: That's the difference between the conversation about MGUS and the actual onset saying, "You have multiple myeloma." That’s the big thing we need to talk about how long does MGUS last before myeloma. I was MGUS probably from birth. That's why I signed up, and they made sure that I understood that. When I was signing up with Dr Ailawadhi at Mayo, they made sure I understood that I was becoming a part of a study, and all my samples and everything were part of the study. It was done in a way that I understood. There's a lot of things of superstition, "They're going to take your stuff and they're going to do this with it."

These are real things you need to talk about. That's what happens to people, they are afraid. Why not help each other. Why not help future generations. But somebody has to explain what that means.

Craig Cole, MD: And the care that you get on a clinical trial is excellent.

Beverly Kerr: Yes, it has been a lifesaver for me. Yes, it is.

Craig Cole, MD: In 2023 and 2024, the clinical trials that we have for myeloma are outstanding, and really only the best of the best of the best drugs and thoughts get to the point of clinical trials. I don't treat other cancers. What we've seen that has happened in myeloma, every time I go to meetings is outstanding. By mistake, I walked into a meeting for a lymphoma, and the audience was only one-third full. There was just few people in there. And I thought, "This isn't like myeloma."

I went next-door, it is packed, because there's so many people working in this disease. Only the best drugs reach the point of clinical trials. There is no better time for safety, for how well they work, and the care that you get is outstanding for this disease right now.

Beverly Kerr: Awesome.

Mary DeRome (MMRF): Yes, yes. It does attract a certain caliber of physician. There's so much exciting progress and things are changing all the time. It's not like some other cancers where there's literally one drug that people get. It's challenging; it's complicated. I think it really sort of piques people's interest, from a physician standpoint, to figure out, "What are the characteristics of my patient and what can I give my patient to improve their outcome?"

Craig Cole, MD: People have asked what's the best thing that I've seen at these meetings.

I say the best thing that I see in these meetings is when I walk in and I see that people have hair and they're wearing sneakers. Because what that tells me is that they're young people working on this disease; the smartest, freshest minds with new perspectives are working on this disease. You need young people doing research on these diseases, to find a cure.

Mary DeRome (MMRF): Good, good. I've got some final questions for everyone. So, obviously, this is a complex issue that requires educating healthcare providers, communities, and patients, among others. So, Dr Cole, what, in your opinion, is the low-hanging fruit that the healthcare community should do to help address the inequities that we've discussed today?

Craig Cole, MD: Yes, I think Beverly had hit on so many of the things that can be done in the myeloma community, especially with patients. I think the summary would be, be empowered. And empowerment comes from knowing options and knowing options is really a conversation. To empower yourself, know about your M protein, know about your risk, your cytogenetics, get second opinions, which I think is really important. I send my patients for second opinions. I do lots of second opinions. Really, the way to break down some of those barriers is knowledge and understanding and empowering yourself.

Discussing, just like Beverly had mentioned, just like Amy had mentioned, discussing side effects of not only the medications that you're getting, but also, the cost of medications. There are things that we can do with the side effects, things that we can do about the cost of care, which is very expensive in myeloma. But one thing that I always try to say at these at these conferences is for patients to teach what you have learned. I think Yoda said pass on what you have learned today.

You're not going to see a Super Bowl commercial that talks about myeloma, but we need to talk about this disease to people. That not only helps patients, but it helps their families. Because everybody knows what melanoma is, which doesn't affect Black people very much at all. Everybody knows what melanoma is, but not a lot of people know what myeloma is. And so, teach what you have learned today, pass it all on. And for providers that are maybe listening, enroll diverse patients, populations in clinical trials; make that a priority.

And definitely get implicit bias training so that, when you sit with your patient, you understand where they're coming from. One thing that we do is that I always think that the medical culture is a very European, very monolithic culture. All of us are bicultural, we all have the culture that we have at our home and then we have the culture within the medical community. And we ask our patients to leave so much of themselves behind, to walk into our monolith of medical culture.

Meet your patient halfway, learn about their culture, so they don't have to leave part of themselves behind, but they can engage the medical culture that we live in, which can only improve the quality and value of care that we give our patients.

Mary DeRome (MMRF): Excellent advice. Amy, what is, from your perspective, one take-home message for our listeners today?

Amy Pierre RN, MSN, ANP-BC: Okay, I'll be brief, because I know we're over time. But I would say that structural racism systemically puts patients of color at an increased disadvantage within our society. But Black myeloma patients can have really improved survival rates and outcomes with equal access to care. Just like Dr Cole said, feel empowered to ask questions and advocate for yourself and continue to spread the knowledge. Because if we continue to increase knowledge about these inequities in the myeloma medical community and the BIPOC community, we can all take strategic steps to really eliminate these inequities that we see.

Mary DeRome (MMRF): Great, excellent. So, Beverly, thank you again so much for being with us today. We've all enjoyed listening to your words of wisdom and your story. So in addition to being a myeloma patient, you've dedicated your career to empowering black, indigenous, and other people of color (BIPOC), and historically marginalized communities, with your nonpartisan organization. So, I suspect that you plan to apply your expertise to raise awareness of multiple myeloma for your community. Do you have any thoughts for patients listening today who may be on a similar journey, or any questions for the panelists, given what we were discussing today?

Beverly Kerr: That's a lot, Mary. I think we covered all of that, and it goes back to always about getting information to the end user. And our organization is boots-on-the-ground, and working with local government, working with local nonprofits, working with our regional, our hospitals and our local oncologists. And I really, really believe that the primary care physicians (PCPs) need more training. I feel like that, with all of that we spoke about today is not new stuff.

It's nothing new, but there was a lot of new information. Like the Promise Study, that should be talked about. It should be part of a visit. And just like we do the patient health questionnaire (PHQ-9) and general anxiety score sheet (GAD-7), there should be a myeloma sheet, that goes into questions we can ask. Maybe we need to make an MGUS sheet. That's where I feel like my expertise works the best. Everything that you do professionally, get it to my hand, so I can get it in front of the people. I'm going to talk to doctors whether I'm a patient or not, because I'm a health educator.

You need to find people who don't mind educating in the community. I don't expect Dr Cole to come out, I don't expect my doctor, Dr Brown, to go out in the community. That's my job, to spread good. I need good solid information, on a sheet, very simple, to give to somebody. And then, to be able to counsel them correctly in what they need, "You need all of this for your team." End-user education is needed. But it's just empowerment.

Mary DeRome (MMRF): Myeloma just is not that prevalent a disease. There's many cancers that are much more prevalent than myeloma. Myeloma is only 1.8% of all cancers, and primary care providers see so many patients, right, and only maybe 1.8% of those patients might have multiple myeloma. So, it's not surprising that they would not be aware of multiple myeloma and the signs and symptoms of multiple myeloma.

It's a huge educational task to really bring this to the community. At the MMRF, we're trying our best to do this and we have a lot of education, not only for patients but also for healthcare providers, on our website. Which is www.themmrf.org. Anybody who's interested in going there and finding some great information on myeloma, please check it out.

On behalf of the MMRF, I'd like to thank Dr Cole and Amy and Beverly for joining me today for this amazing conversation.