

Addressing Bias and Disparities in the Care of Patients with Cancer: A Call to Action for Associates



CMEO Podcast Transcript

Dr. Monica Peek:

Hello, and welcome to a very special CMEO Snack that is part of a series I'm leading on diversity, equity, and inclusivity with CME Outfitters. Today's CMEO Snack is entitled, *Addressing Bias and Disparities in the Care of Patients with Cancer: a Call-to-Action for Associates*. Today's program is supported by an educational grant from Walmart Incorporated.

I'm Dr. Monica Peek, and I'm the Ellen H. Block Professor of Health Justice in the section of General Internal Medicine. I'm also the Associate Director of the Chicago Center for Diabetes Translation Research and the Director of Research at the MacLean Center for Clinical Medical Ethics, all at the University of Chicago in Chicago, Illinois.

I am so delighted to be joined today by my distinguished colleagues, Dr. Ana Velázquez Mañana and Stacy Hurt. Ana and Stacy, could you please introduce yourselves to our guests today?

Dr. Ana Velázquez Mañana:

Hello, and thank you, Dr. Peek. I'm Dr. Ana Velázquez Mañana. I'm an Assistant Professor in the Division of Hematology/Oncology and the Assistant Director of Diversity, Equity, Inclusion and Accessibility for training at the UCSF Helen Diller Family Comprehensive Cancer Center in San Francisco, California. I'm a medical oncologist and treat lung cancer, primarily at UCSF and at our Safety Net Hospital, San Francisco General Hospital.

Dr. Monica Peek:

Welcome.

Stacy Hurt:

Hello, and thank you, Dr. Peek. My name is Stacy Hurt. I'm a patient engagement consultant based in Pittsburgh, PA. I've worked 25 years in various functions across physician practice management, operations, training, and development in pharmaceutical sales, and along my career it was disrupted twice by two devastating diagnoses: my son with a rare disease with a chromosome abnormality, so rare he's one of three known cases in the world, and myself with a stage 4 colorectal cancer diagnosis in 2014, of which I am now 7 years cancer free. What I saw along the way was the large gap that existed between those of us who delivered care, maybe worked in industry, and those of us who consumed care.

So, I forged a consultancy to close those gaps and amplify the voice of the patient and the caregiver in clinical decision-making. Thanks for having me.

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Dr. Monica Peek:

Thank you both for being here and for bringing your expertise to the conversation today in two different areas. I'm really excited to have you with us.

We're going to jump right in and talk about something that's difficult but that's really important to our conversation today, and that's the impact of racism on health care. There are really a lot of different kinds of racism. There's structural racism, which is really the policies, the procedures, the things that are in place without any necessarily malintent that differentially impact people's access to care, their access to the resources, like Stacy was just talking about, who can afford health care and those things in the community that impact whether or not people actually get diseases in the first place. And the other kind is the kind of racism that we normally think about, which is like prejudice plus power. And both of those exist within our healthcare system.

The implicit bias and these ingrained systems of racism have impacted all aspects of patient care. What that has done is erode the trust from marginalized communities, particularly racial and ethnic communities, and other socially marginalized communities because of people's personal experiences and not feeling valued, not feeling heard, and feeling like they've been treated poorly. And it has resulted in people being less adherent to care, people not returning for care, all kinds of things that negatively impact health in addition to them not just receiving the right kind of care in the first place.

Many of you may know that there are certain populations that have a higher incidence of diabetes, and there are some specific Native American tribes who have had genetic markers that have identified them as such. The Havasupai Tribe came to Arizona State researchers and said maybe our tribe is like that and maybe you could find some genetic markers, and we can sort of figure out how to do things differently within our population.

What happened is that their blood samples were then used without their consent by other researchers to do studies that the tribe knew nothing about, looking at things like inbreeding and increased risk for substance use disorders and schizophrenia and other things that were really stigmatized, stigmatized diseases and conditions. So, the tribe sued and settled in 2010 for I think it was 1.7 million dollars. That's one example that has still impacted the trust between that tribe and the healthcare system in general and specifically the healthcare system from Arizona State.

Ana and Stacy, is there anything else you'd like to add before we move into our discussion today?

Dr. Ana Velázquez Mañana:

I think that, for me, it brings the point home, and it's very close to my heart because many people don't know this but Puerto Rico actually also has a longstanding history of mistrust because trials for anti-contraceptive pills were performed in the island and, similarly, forced sterilization. In between the thirties and sixties, up to a third of Puerto Rican women were sterilized without their consent or without prior understanding.

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Dr. Monica Peek:

Yes, it's a lot. When people are marginalized and don't have as much power and they're vulnerable, lots of bad things happen to them. Then we wonder why people are suspicious about the COVID vaccine or other things when we say, "Hey, we've got some great things for you!" and want to know why people don't trust us more when we have good things we're trying to roll out to save their community and the community at large.

So, what we're trying to do now is sort of think about those things as they relate to cancer care. I know that the Walmart community has had discussions already about social determinants of health and what they are and how they can impact lots of care in lots of different ways. Some of those may be delays in cancer screening.

Ana, do you want to talk a little bit about social determinants of health?

Dr. Ana Velázquez Mañana:

Sure. We know that social determinants of health are the condition of the environment in which people are born and live and thrive and work, but similarly impact their care and their ability to be healthy, have function, and engage with people around them, with healthcare systems, with other things, and lead to differences on your quality of life and risk.

There are certain things that we know commonly that are socioeconomical related, like your education, how much money you make, and if you're employed or not, that impact health care, but there may be other things that are related, for example, the environment and the area in which you live. If you live closer to factories that have a lot of pollution, that may decrease your health and the conditions that you have.

Dr. Monica Peek:

Absolutely. And then can you talk a little bit, Stacy, about how stigma and bias can negatively impact cancer rates?

Stacy Hurt:

Absolutely. I'm a colon cancer survivor. It's very stigmatic, and I think that contributes to part of the reason why colorectal cancer is the second leading cause of cancer death as well as the third leading diagnosed cancer, which is because people don't want to talk about poop and they don't want to talk about problems with their stomach or their bowels or constipation or diarrhea or any of that.

I just want everybody to know that it's okay, and that these are normal body functions that each of us do every day. So, to have those conversations with your doctor is completely normal and healthy, and when you, if you have any symptoms, if you have blood in your stool, if you have fatigue or bloating, it's okay to come forward and to talk to your provider about those.

Back to what you talked about, Monica, I acknowledge there is a huge trust problem in this country. There's a huge misinformation problem in this country. Unfortunately, cancer is the one thing that unites all of us. We've all been impacted by cancer. We all know somebody who's been impacted by cancer. But also acknowledge that

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when we do go to the doctor we want to hear that information from somebody who looks like us or maybe somebody who speaks the same language as us, and that therein builds that trust.

We're working hard to bring forward more providers of color and multi-language delivery of care. But, yes, certainly this stigma is a problem and it results in cancer being diagnosed in later stages. One thing that I can encourage people to do is to absolutely get your screenings done on time and to avoid that and be more proactive with your health. Take it from me, I couldn't have avoided what happened to me diagnosed at stage 4, but certainly now as a patient advocate I do advocate for early, on-time screening.

Dr. Monica Peek:

Yes. And one thing that I will say is that a lot of people can have some of their screenings done at their local Walmart because they have a lot of health facilities. There's a Walmart in many communities, so no one is too far away from a place where they can get some of these screenings done. Thank you both for talking about some of the social determinants of health as related to cancer rates and treatments and screening.

I want to switch gears a little bit and talk about real-life issues. Ana, can you talk about what has impacted you the most as a lung cancer specialist?

Dr. Ana Velázquez Mañana:

In lung cancer in particular, there's a lot of stigma similar to colon cancer, and it's related to tobacco and smoking. The fact that nicotine and smoking are seen as something that is negative for people makes it challenging for patients to adjust to having this new diagnosis, to go for screening tests, and even for providers to recommend screening because, unfortunately, we all have our own biases and people may put blame on patients, and it's part of what the stigma and process is. And some people may not believe that screening is worth it if somebody's going to keep smoking, or they should have not smoked to begin with. And the reality is that any person who has lungs can get lung cancer. So that's what I would say is the norm by which we should be thinking and where we should be starting.

I would say there are so many patients I've seen who have had respiratory symptoms and a cough and a cold that just will not go away and keep going to their doctors, and doctors in clinics are overwhelmed are overstaffed, and you may see a different person every time in which they don't get in context that you already got antibiotics three times or had a virus three times and still are coughing. So, there is a role for everyone on the team, whether it's a nurse, whether it is the person in the check-in, whoever it is who is seeing that this patient keeps coming again and again for the same thing to say, "Hey, have you asked your doctor if there's something else that is not an infection wrong with you?"

Dr. Monica Peek:

The pharmacist who keeps filling the same prescriptions.

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Dr. Ana Velázquez Mañana:

One hundred percent. The pharmacist, the check-in person, any, I mean anyone can have the role in identifying something that is wrong, and ask “Why are you having all of these infections?” And you, as the patient, can empower yourself and ask the doctor, “Is there something else? Can I get a chest X-ray or a CAT scan?” depending on what it is and the symptoms that you’re having. We never know who’s the person who’s actually going to catch cancer on somebody else.

I think one of the classic examples that we hear is hairdressers who may see a mole on somebody’s head, and this person then ends up having melanoma, which is a deadly skin cancer. I think all of us and our audience should take that role if you can, and you can really empower people and help them connect them with care.

Dr. Monica Peek:

Absolutely. I really like that idea of everybody empowering themselves and empowering others no matter what role you have on the health care team. And, Stacy, that’s a lot of what your organization does: advocate and empower. Tell me one of the most impactful experiences you’ve had in your role as your organizational lead.

Stacy Hurt:

If there is one thing that I feel absolutely passionate about it is that you are your own best advocate. And if there’s one thing that I tell patients every day, it’s that you know your body best. If you have the gut suspicion that something’s wrong, it probably is and it warrants a conversation with your health care provider. It is your right to ask for that. You are entitled to the dignity that you deserve in coming forward with that issue, and you should be treated as the entire human person you are in bringing that forward. I hear a lot from elderly people, people of color, people in other underserved populations that they are intimidated and that they feel dismissed, and nobody should ever feel that way. You should feel absolutely empowered and within your rights to bring forward any sort of health issue that you have.

As I said, I’m a colon cancer survivor, and every part of your body is beautiful. This is what I tell when I give talks to the assemblies of the middle school kids and everything, but it’s a great message for everybody: no matter what age you are or where you come from, every part of your body is normal and beautiful and you should be able to have a free conversation with your health care provider about it.

Dr. Monica Peek:

Absolutely. And that’s one of the things that I study a lot: patient-provider conversations, shared decision-making, and the power that patients and doctors have. Doctors have most of the power, and that balance is a lot more unequal when there’s discordance or a difference, by race or class or immigration status, or literacy levels and other things. So, the more socially marginalized a person is, the less likely they are to feel like they have the right or that they have the skills or the power to have those conversations. You’re right, everybody has the right to be able to ask questions and to go on their intuition and say, “I know my body. Like you may be the physician, but I am living in my body, and I think that something’s wrong. And so let’s have a conversation about these symptoms

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that I'm having." You're exactly right, and thank you for reminding us all about the importance of advocacy and opening discussions with our health care providers.

So, where to start? Ana, I know that we're getting close on time, so I don't want to spend too much time on this slide, but what are the questions from this list that might be the most important for someone to start with?

Dr. Ana Velázquez Mañana:

I think that when we think about screening, the top things are to think of your age, with your identities, what screening tests you should be getting, and think about based on you as a person, in your family history exactly what tests you should get. If it's somebody who has a strong family history, for example, and risk factors of breast cancer, then the regular guidelines do not apply to you.

So, make sure you ask those questions: "This is my age, this is my gender, this is what I've had done, and this is my family history. What tests should I be getting for my own health?" Screening is part of our health.

And then, I think the other two key things are where can you get those screens and if there are things that you can do at home for some of those screening tests if they're able to be done at home or at your local facilities, and whether or not they're covered. We know that costs are something scary for many people. I would say that insurances should cover preventive health care and screening test. If yours does not or you are uninsured, then ask about programs that exist for people to get screening tests and be supported with the cost of that.

Dr. Monica Peek:

Absolutely. Thank you both for such important insight today, and for all the great work that you do.

I want to recap with the main takeaways from today's program: to recognize our own biases that we may carry, to respect each patient's story and how racism may have impacted their perspective on health care, to listen and be empathetic, to know that screening is the key with regard to oncology (many diseases but particularly oncology), and to be empowered for your own care, for your family's care, and for anyone who is seeking care. I would encourage us all to check out these resources to learn more about what was being discussed today.

Thank you all for tuning in. I'd also like to ask you to complete the online evaluation because we really want to hear from you: what you liked, how we can improve, and what are the additional topics you'd like for us to address. You can also participate in our other diversity and inclusion activities.

Thank you so much for your commitment to education on diversity, equity, and inclusivity. When we know better, we do better, so thank you so much for being a good human.