

Health Inequities in Inflammatory Bowel Disease Care



CMEO Podcast Transcript

Monica Peek:

Hello and welcome to a very special podcast that is part of a series I am leading on diversity, equity, and inclusivity with CME Outfitters. Today's CMEO cast is entitled Health Inequities in Inflammatory Bowel Disease Care. I'm Dr. Monica Peek and I'm the Ellen H. Block Professor of Medicine in the Section of General Internal Medicine at the University of Chicago. 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 here at the University of Chicago. I'd now like to welcome Dr. Sophie Balzora. She's a Clinical Associate Professor of Medicine at the NYU Grossman School of Medicine in the Division of Gastroenterology and Hepatology at the NYU Langone Health in New York, New York.

Sophie Balzora:

Thank you, Monica. Good to be here.

Monica Peek:

Wonderful to have you. I'd also like to welcome Dr. Nana Bernasko, who is an Assistant Professor of Medicine in the Division of Gastroenterology and Hepatology at Penn State Hershey Medical Center in Hershey, Pennsylvania. I'm honored to have you joining us today and am really excited for our discussion.

Nana Bernasko:

Thank you so much. I'm happy to be here tonight.

Monica Peek:

Wonderful. Let's jump in with our learning objective for today's program, which is to analyze the influence of unconscious bias, health disparities, and health inequities on the care of patients with inflammatory bowel disease (IBD). I want to remind our audience that this CMEO podcast is a continuation of our initiative to address unconscious bias, health disparities, and racial inequities. We're building a comprehensive library of educational activities addressing these important issues, and today's activity continues the discussion in the area of IBD care. On this slide are the titles of the activities in this series with links to each of them. To view any of the programs, simply click on the activity title.

If you participate in at least three of the programs in our D&I Hub, you'll also be eligible to receive a digital badge demonstrating your commitment to education on diversity, equity, and inclusivity. As we begin to address IBD care disparities, I want to review some foundational points regarding historical racism that can help us all remember how we got here. We've done previous programs that cover these topics in depth, and those programs can be found in our D&I Hub. I just want to make sure that we recognize that we'd be doing a disservice if we didn't take a moment to recognize that we have a groundwater issue that we have to address, which is structural

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racism, and that sets the backdrop for the conversation that we're going to have today. Systemic racism/structural racism manifests in lots of different ways, including the disproportionate allocation of the things that we talk about a lot right now: social determinants of health, food insecurity, housing instability, and barriers to transportation.

It also affects things like poverty and crime and things that are in our social and built environment. It affects things that are in our natural environment also, like the disproportionate rate of toxins and pollutants that are in our water, our air, and in landfills that are more likely to be located next to racial and ethnic minority communities. And amongst the list of things is that it directly impacts bias and subconscious and conscious bias that health care providers have, and that's a lot of what we're going to be talking about today. The impact of these kinds of structural racism has a direct impact on our health, the indirect effects of systemic racism that manifests in lots of different ways, such as unequal access to health care, differential or disparities in the kind of care that's delivered to actual patients who are deviations from standards of care with certain populations of patients.

It affects the stress that patients who are exposed to racism have. That stress then translates into dysregulation of pathophysiology and changes in epigenetics that alters the actual body mechanics of people who are exposed to racism and discrimination and increases the risk for cardiovascular disease, cancer, chronic lung disease, and many other diseases. It can also directly manifest in mental health disease like depression, anxiety, PTSD, and others. And it impacts long-term things that we are always constantly thinking about from a public health perspective, like how engaged people are willing to be or retained in our healthcare systems and how likely people are to uptake new technologies and new things like COVID vaccinations when they become available on the market, new medicines, new technologies, new innovations.

So our ability for marginalized populations to not be on the disparate end of what's available in the healthcare system is in part a reflection of structural racism within our communities. That's the context in which we're operating in general for all of our sessions that I want to just make sure that we've reviewed before we dive into the specifics of any of our clinical conversations. Now that we've set that context, we're going to turn our attention to racial disparities in IBD. Nana, can you begin our discussion and talk about the profound increase in the incidence of IBD in racial and ethnic underserved populations?

Nana Bernasko:

Absolutely. Rates of IBD have been increasing in all racial and ethnic groups, but the distribution of growth is unequal. In a study that was done by Aniwaniwa and colleagues, they looked at the incidence of IBD by race and ethnicity in a population-based inception cohort from 1970 to 2010. They saw a 39% increase in IBD incidence in White patients compared to a 134% increase in non-White patients. This is phenomenal. Why is this happening? Let's look at some of the factors. There are delays in diagnosis and treatments in underserved, underrepresented populations because for some reason IBD is under-recognized in this subgroup of people. There are so many patients I've had contact with who show up in my office who say that they've been having symptoms for a long time but they're always told it's in their head or that they're drug-seeking or whatever the reason is, so it seems like their symptoms are dismissed more often than not.

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This leads to the underdiagnosis of IBD in these subgroups of patients. Other things that can happen with these particular groups of patients is that there is a disparity in the care of these patients. When you look at Black and Hispanic patients, they report avoiding visits more often due to cost or transportation concerns. There are higher rates of IBD-related hospitalization and mortality in non-Hispanic Black patients. Other things that they report in Black patients is that they report there's decreased access to GI specialist care. Also, there's decreased use of biologics and newer therapies in Black, Hispanic, and Asian patients. Increased rates of emergency department (ED) visits in Black patients with IBD are also noticed in this group.

Monica Peek:

One question I have for you: When symptoms are sometimes not validated, I've always wondered if people are more likely to be diagnosed with irritable bowel syndrome (IBS)?

Nana Bernasko:

Absolutely. I have quite a number of patients I see in my clinic who have never had any sort of studies done. Maybe they get an abdominal X-ray and that's basically it. They're told that their symptoms are IBS. As we know, IBS is a diagnosis of exclusion, so how could you rule that out without actually doing any further testing on that patient? By the time that patient gets to you or somebody takes them seriously, their disease is further gone than anticipated and that's because their symptoms were ignored. They were told that it was in their head, they were making it up, or they were seeking pain medicine, which is what I hear a lot too.

Monica Peek:

Sophie, what are some of the driving forces behind these disparities?

Sophie Balzora:

That's a great question. I think there are many that have been looked at, but we don't have all the answers. I think that both of you have laid a good foundation as to why we're seeing the disparities that we do. But things that have been looked at, which were touched upon briefly by Nana, were medical management optimization. There have been studies that have shown that it's unfortunately difficult to find a gastroenterologist, let alone an IBD specialist, to treat patients who are considered to be underserved or minoritized patients. When you have a patient who is less likely to see an IBD specialist, that spills into the fact that those people who are non-IBD specialists are less likely to be comfortable administering the medications that the patients require. So, the more severe disease requires certain medications like biologics, other immunosuppressants. If they're not comfortable with that because they don't see patients with IBD frequently, then it does a disservice to those patients who we're now seeing in much higher numbers who are suffering from IBD.

Then of course there's cost, and that feeds into the social determinants of health. These medications are expensive. Though there are some programs to help lower the cost, sometimes that out-of-pocket cost is still exorbitant and too difficult for patients to pay who already have all these other burdens to deal with. When we think about the issue of financial toxicity, which I think originally came out of the cancer literature, it's definitely

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applicable here. We see that things like financial toxicity play a huge role in other things like mental health issues and things that we see in higher numbers in populations with IBD.

I think the last thing that is very interesting to note came out of a study that was from Chicago, I believe, with Dr. Adjoa Anyane-Yeboah and colleagues, where they looked at patients with IBD and celiac disease starting at the presentation of iron deficiency anemia. Routinely, for patients with iron deficiency anemia, particularly those who are postmenopausal or those who are men, we think about things like malabsorption, and some of those things include IBD and celiac, which are common culprits. They found that those with public insurance were 91% less likely to get appropriate workup for IBD or celiac disease when presenting with classic symptoms. So think about all the people you're missing and why we are missing these particular groups. I think that feeds into the bias. It's just a patient that you don't normally think of as having IBD or celiac disease, and that's something that is incredibly detrimental and absolutely feeds into the disparities that we see.

What was also found in that study was that White and Asian patients were more likely to have private insurance than Black and Hispanic patients. It aligns well with that other idea that these people are less likely to receive the care they need. We know that people have ongoing symptoms, which can be representative of complications of the disease. It's less likely that the medications that they need are actually going to work once you administer them. As Nana had said, sometimes people are too far gone and that inflammation then becomes scarring with more serious complications. Those medications that they needed when they first presented with symptoms that they were deprived of can unfortunately feed into worse outcomes.

Monica Peek:

Absolutely. I think this is a great time to talk about the cost because some of the medications that you all are prescribing are so exorbitantly expensive, and it reminds me of insulin because I'm a primary care physician. Insulin has become so exorbitant that it made it to Congress for them to be talking about. One of the things that I realized, I actually wrote a piece about it in *The Lancet* last year, is that the United States is so uniquely different from our other Western counterparts in how we regulate our medications. I know that people go to Canada for medications that are cheaper, but the entire way that we regulate the pricing of medicine is so uniquely different. The cost is so exorbitant here compared to other comparable countries that we are really doing our marginalized patient a disservice and those are oftentimes the ones who are having a higher burden of disease. So it's a double whammy in that they're more likely to get some of these diseases sometimes and are the ones who are the least able to pay for them.

Sophie Balzora:

Right. Other things that we think of when we have a patient with IBD in front of us is health care maintenance. That's a huge area of care that is oftentimes neglected or it's difficult to know who is going to be the one responsible for that care, things that need to be done routinely, but we need to especially pay attention in patients with IBD for cancer, colorectal cancer in particular. When we talk to patients, particularly adults, who have extensive colitis, one of the main things that we're trying to prevent is colorectal cancer. When you know that there are already disparities that exist that are both racial and ethnic in origin, and then on top of that you think about the disparities that occur in IBD, it really sets patients up for failure.

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We need to be incredibly cognizant of this reality. When patients are getting suboptimal care they are then more likely to suffer from colorectal cancer and have issues surrounding pregnancy and getting the appropriate prenatal care, vaccinations, appropriate eye screening, and other types of screening that can be life-changing and life-saving. We need to understand that there are certain resources that aren't being allocated appropriately because people are not being seen by particular specialists who know to think about these things on a regular basis. We talked about it before: depression. Think about all of the stigma that's attached to depression and mental health issues, and that is even more pronounced in certain populations. Then you see that that is even in higher incidences in patients with IBD. Again, it's one thing compounding on top of another.

So when there's less access to mental health care specialists, when people are more reticent to see a health care professional about their mental health illness that's tied to this now-chronic disease that they're suffering from, that they can't pay for their meds, and they have to go to frequent visits for and miss work for, of course it's going to cause a lot of physical stress and mental stress, all of which, again, can feed into poor outcomes and widen disparities.

Monica Peek:

We're going to get to this later, but I just feel like I want to say it right now because we have a colleague in common who is skilled at doing colonoscopies when people are awake. He does that specifically because he knows that many African American patients don't have a ride and so they can't get the colonoscopy if you don't have someone who will come and wait for you. I had a patient who had arrived, but he was like, "I am never going to be knocked out and have somebody in my behind." He made me actually come with him to the colonoscopy. He was awake. Our colleague actually loved the procedure. He asked, "Can I do this next year?" No, you cannot.

Sophie Balzora:

Some people love to clean up.

Monica Peek:

I can see all this stuff. He fell in love with our colleague but he was like, "I do this because so many of our patients need this additional service and can't have it because there are these additional barriers." Like you said, so many of the patients with IBD need colonoscopies more often because they're at increased risk. So part of what we have to do as a professional is lean into those additional needs and be willing to go above and beyond our skill set to meet patients where they are. A lot of us may or may not be willing to do that. This colleague that we have in common is an African American man who's going above and beyond.

Sophie Balzora:

It's well said that it is a skill set. Sometimes there's a situation that arises where there are patients who can't have a procedure done in our office because of their body mass index or because they have certain heart or lung issues, and I offer them a procedure without sedation. They say, "Who would want that? How would anybody choose that?" and it doesn't even come in their thought process that some people don't have anyone else to lean on. Some people, their guardian or significant other person that they rely on, is wheelchair-bound and would

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need Access-a-Ride and it would be a whole issue, or this person has to go back to work, or they actually don't have sick days to spare.

That never even comes into play for other people. I think that that's a privileged position that some people have, but it's important for everyone to realize that this is an issue and that's why we need to be creative about ways, like having procedures without sedation and other means, ride shares, those sorts of things to help break down and mitigate some of those barriers that are quite common. Sometimes people are embarrassed or hesitant to say that that's the reason and so it's on us, like you said, with a skill set to bring those issues to the forefront so people can be more comfortable letting us know what those barriers are.

Monica Peek:

Absolutely. We've been discussing some of the disparities. How do we assess contributing factors that are leading to the differences in IBD treatments?

Sophie Balzora:

The wonderful thing about IBD, especially I think in the past decade or so, is that there are so many new medications on the scene. It's really fantastic to have an opportunity to offer patients different potential medications that may work well for them. I think, even with the short time that I've been practicing, it's just like boom, boom, boom, there's a new medication every week or so that's getting approved by the U.S. Food and Drug Administration (FDA), which is great, but that doesn't mean that everyone has access to it. As we were saying before, certain people don't have access to an IBD specialist. What does that mean? It means that those newer medications that can sometimes be more expensive are not going to be at their disposal. A lot of times when we see those newer medications being used, it's in patients who've tried and have not responded to other medications that are traditionally used. So those people are already in a worse position.

The fact that they may not have access to a new medication or they may not have access to a clinical trial that allows them to try this medication is a huge deal and another source of disparities. Also, some of these medications can be complicated and have a lot of potential adverse effects. It's kind of a laundry list of things to go through. It's sometimes one of the main reasons why patients don't want to start a medication, understandably. But having that, what we call patient activation, having that confidence in, "Hey, I know what my disease is about. I know what my extent of disease is. I know what surgeries I've had. I know when my last colonoscopy was and I know what it showed," you see some of these people who are extremely savvy and educated about their disease and others who are not so confident in understanding not only their disease but also what the treatment plan may be, especially if it undergoes a lot of changes if you're switching meds, if you have severe disease.

When you look at White patients compared to, for instance, Black patients, which is a common comparison, you'll see that the confidence isn't really there and that is due to so many different things. And, Monica, as you mentioned before, the social determinants of health, those midstream determinants like education attainment and housing and environmental toxicities, all play into these results that we're seeing. This is not something that's in isolation.

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Monica Peek:

That's right.

Sophie Balzora:

Sometimes when you see a patient in front of you, you're going to say, "Hey, they just don't care about their disease or they just don't get it," but there are so many factors that go into that that are beyond their individual control, and I think that that's what studies like this really represent. There's a huge difference here when you look at patients who are White and how confident they are in their treatment plan versus patients who are Black and those who are extremely confident. Only 15% compared to 45% of White patients. That's a huge difference that we really need to narrow.

Monica Peek:

It absolutely is. A lot of my work is implementation science and trying to get behavioral interventions, so we always measure self-confidence because that is the most proximal thing that happens before behavior change, which makes sense. If you don't feel confident you can do it, you're not going to even try. Whereas if you do, yes, you can do it, then you're more likely to try and engage in that behavior. So that is a significant thing to measure and to understand. Now I'm going to loop you back into the conversation because we had just started talking again about social determinants of health and how it's related to things like self-efficacy and health outcomes. Why should we pay close attention to these upstream and midstream determinants, and what are the resulting downstream health outcomes? Help us think about these things.

Nana Bernasko:

Sure. We've already talked about some of these upstream determinants. We talked about racism, poverty, neighborhood violence, underinsurance, those sorts of things that feed into the midstream determinants, which are the lack of social support, financial toxicity, poor housing conditions, food insecurity ("What do you mean I'm supposed to eat a healthy diet?" "I can't afford a healthy diet."), and some things like poor adherence ("What do you mean I have to inject myself every 2 weeks or once a month?"). Those things feed into the downstream health outcomes, which are delayed diagnosis and increased disease severity, which lead to IBD flares. If you look at that patient who is not seeking their care from an IBD specialist, they're probably going to urgent care or seeking their care in the ED. What do they do in those situations? They give them a lot of steroids and send them on their way to follow-up with a non-existent provider, and it's the same cycle over and over again.

These lead to hospitalizations and prolonged stays in the hospital, more mortality for this patient, and even disability. So it's so important that we look at it upstream and midstream and how it really affects the downstream healthcare outcomes for these patients. We can't look at each in a silo, basically. Also, things that we need to take into consideration, as I just mentioned, are that there are some pretty telling downstream health care outcomes when comparing Black patients with IBD to White patients with IBD. Let's look at a bit of that in more detail. With unequal access to appropriate care for the Black African American patient, they're less likely to have annual visits with a gastroenterologist or an IBD specialist, as I said before. They may be seeing an urgent

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care professional or have ED visits as their routine care. Black and African American patients are two times as likely as White patients to visit the ED.

There is no continuity of care. They go to the place that they know they're going to get the fast medications, which are the steroids. Then these patients are less likely to receive treatment with anti-tumor necrosis factor (TNF) because, again, they don't have access to specialized care and so they're going to places that they can get the quick fix. These, in turn, as I mentioned, lead to higher hospitalization rates, increase in length of stay, and it goes forth with mortality for these patients. So these patients tend to do poorer overall, again, because they just don't have the appropriate access to the appropriate care.

Monica Peek:

This is a story that is not unique to IBD as far as people who are utilizing the emergency room because of a lot of reasons: the time of the day that's convenient for them, suddenly that's not 8:00am to 5:00pm. I find that's true for me. I'm a busy professional and when I'm available, all the businesses that I need to use are usually closed, so it's understandable how when people have so many things that they're burdened with, when they are ready to seek health care, what is available might be the emergency room or when things are really getting out of hand. But when you have things like severe IBD, those can become medical emergencies.

Nana Bernasko:

Absolutely.

Monica Peek:

Sophie, let's talk about another set of outcomes that are really important, and those are stemming from social barriers. What can you share with us about that?

Sophie Balzora:

There's a means of trying to tease out different parameters that relate to the social determinants of health that Nana was going into and create a point system to see the higher the number of points, the more likely someone is going to have negative outcomes, things like were they born in the United States or did they immigrate from somewhere to here? What's their housing situation? What's their level of educational attainment? Do they have a community, like a church community or some other place that they can go to have that sense of support? All of these things definitely play into health, and these are social determinants that inevitably have some tie to patients' ability to achieve their best health or health equity. What we see in IBD is that patients who had these higher social barrier scores did more poorly.

Not only did they have more active ulcerative colitis disease, but they also suffered from depression at higher rates. They obviously could sense that they had poor overall health that seems very apparent. So it's not just about how they feel but this is actually affects their disease. Again, that stress, that mental stress, that lack of social support that can feed into financial toxicity and just how overall well a person is absolutely can affect their disease, and so that's something that we need to really understand. Again, this is not siloed. We have to look at

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the big picture. If we're going to make real change, real lasting change with IBD in these underserved and historically disenfranchised groups, we have to look more with a bird's eye type of view because it's really the same groups over and over. It's not a coincidence.

It's so important to recognize the history that led to these outcomes because, again, every chronic disease that we see is the same people suffering the most. This is not new news. I think that what we're recognizing more is that, of course, there's more of a population who are Black and Brown who have IBD. So it's good that this is being studied more and more often, but it's sad to see that in any of the fields that all our colleagues practice in, whether it's cancer, heart disease, diabetes, obesity, COVID, chronic obstructive pulmonary disease (COPD) – all of these things, and imagine having all of those issues plus having IBD. It makes it almost like an impossible hill to climb for some people.

Monica Peek:

Absolutely. As a primary care provider, I see the bread-and-butter conditions that I consider to be the diseases of oppression, the things that we know that have been linked to the path of physiological abnormalities that occur from chronic exposure to racism. I was part of a study that was done here in Chicago in two of our epicenters of violence. We were interviewing middle-aged people with chronic diseases who were not perpetrators of violence or victims of violence but just lived in a neighborhood and they had higher levels of blood pressure. In some of the patients, their levels of blood pressure were so high that, based on what we know from the Framingham Heart Study, increased their risk by 50% of having a heart attack or stroke. We know that community violence, social isolation, hypertension, and racism all mixing together impact the health of our communities, and not just with one disease but with multiple diseases. Their telomere shortened and they suddenly have this range of strange diseases that really shouldn't be going together. We see structural racism play out in our communities in the very people who live in those.

Sophie Balzora:

Right. I think what really drives home with this discussion is that it's not these individual behaviors, right?

Monica Peek:

Right.

Sophie Balzora:

I think that's what we're used to learning. That's what we're used to thinking. That's obviously the easier way to think and probably the lowest-hanging fruit to try to change, but ultimately, without changing these systemic issues that we're discussing, there's really not going to be an end to this.

Monica Peek:

Absolutely. Nana, I want you to weigh in on achieving equitable IBD care. We've talked a lot about what we know, as knowledge is power, and you guys have been extremely helpful in just helping me think about IBD care and

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helping me see how this is just another example and how this paradigm applies to how I think about diabetes and many other diseases. How can we shift our focus and start thinking about equitable IBD care? Nana, where should we start?

Nana Bernasko:

First of all, we have to screen for the social determinants of health to identify patients at risk. It's so important that we screen because not every Black or Brown person who walks into your office is going to have this issue.

Monica Peek:

That's right.

Nana Bernasko:

We need to make that distinction. We have to screen and not assume that anybody who walks into the office has the same issues to deal with. Next, we have to connect these patients to available resources. We're the ones with the knowledge and so hopefully we're the ones driving these patients to resources that will be able to help them. These resources include faith communities and local organizations. I personally refer my patients to support groups that I know exist within the IBD community. If you're in a big institution that has social workers or case managers as well, they are very, very important in the care of these patients and they can help out with insurance and financial assistance.

We have a patient financial-assisted program here at Hershey, which I refer most of my patients to who are having issues affording some of these really expensive medications. They have been really helpful in working on behalf of their patients to get affordable medications or even free medications for these patients. It's really important that we, as providers or as clinicians, have access to these resources or information on these resources in order to disseminate that information to our patients. We need to plug them in so that they don't feel alone and that we put them in a position to be successful because this disease is not going to go away magically. It's something that they live with and therefore they have to be able to manage it effectively.

Monica Peek:

Sophie, do we have any data about if outcomes improve when we improve access to expensive treatments such as anti-TNF?

Sophie Balzora:

That's a good question. I think it's interesting to see what will happen when people are given the access to care and the type of medications that their disease requires. When you see that Black patients who are exposed to anti-TNF who have Crohn's disease and ulcerative colitis, their outcomes improve and they more mirror that of their White counterparts. So that's very promising to know and an impetus for us to do better and try to change how the delivery system works and change how people can have better access to IBD care.

Monica Peek:

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Absolutely. Thank you for evidence-based medicine. I think a lot about team-based care. I've been talking about this for more than a decade and we're now in a place where that's considered the standard of care, but a lot of the places really are not living up to that standard. We're not having people work to the top of their license. Nana, I'm going to toss this one to you. How and why should we educate the entire provider team and what would that look like?

Nana Bernasko:

That's a very interesting concept. I will use an example because this actually happened to me last week. I went to see my primary care provider. I have a bit of an unusual name and so when the nurse called me back, she was like, "Did I say your name right?" And before I could even answer, she walked away from me. The entire time that she was rooming me she was very condescending and very dismissive to me. We were talking about something. I needed an EKG and she asked if I had had one before and I was like, "Oh, probably when I was in nursing school. We practiced on each other." And in the same breath she turned around and asked me if I finished school. I was like, wow, okay. I was completely speechless. For me, that was so negative in that if I hadn't really had an established relationship with my own primary care provider, I probably would not go back.

It's so important for the Black or Brown patient who's walking into that office who may already have some hesitancy being there in the first place. Then for you to be judged based on your skin color, not even from the doctor or the provider who's taking care of you but the person who may be checking you in at the front desk or the person who's taking your temperature who doesn't bother to explain to you the different steps that they're taking, or that they're making an assumption based on your skin color that you are not educated or you have absolutely no idea what's going on. It's so important that the health care team, from the person who checks you in to the person who checks you out to the pharmacist, the nutritionist – whoever is touching that patient, is aware of implicit bias and maybe even explicit bias as well.

I think it's so important that we focus on training on discrimination and racial disparities in health care, recognizing and addressing these biases from a non-clinician staff bias, meaning let's not just focus on the provider who's taking care of the patient but the whole group because that patient has that experience throughout their visit. I walked out of that office feeling very defeated, feeling very vulnerable and insulted.

Monica Peek:

Violated.

Nana Bernasko:

Yes, violated. That's the word. It was just beyond me that she would think that I didn't even finish school based on nothing. That was my introduction to her. But again, imagine that patient who's super vulnerable who's walking into that office; they're probably not going to come back.

Monica Peek:

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I think about that a lot because as a physician I have been a patient a lot and I think if I have encountered these things at a hospital where half the people know me, because I always get my care where I work and I am super empowered, what must the experience be like for patients who don't have the information, the social connections, whatever, to try and navigate their way through this system? What are they experiencing? What kind of humiliation, what extra layers of shade and discrimination are they going through?

Nana Bernasko:

Exactly.

Monica Peek:

Because I have been violated multiple times with my experiences, it just gives me pause to reflect on others who don't have the same social capital that I have.

Nana Bernasko:

I couldn't agree more.

Monica Peek:

Sophie, what are we going to do about this? How can we make our teams more diverse?

Sophie Balzora:

We don't have the luxury of ignoring the problem or not addressing it because though it is everybody's problem, you see that there are certain people who are consistently trying to address it more than others. But when you look at the representation of practicing gastroenterologists, the latest American Gastroenterological Association (AGA) data from 2018/2019, there is a huge disconnect between what the practicing gastroenterologists represent in terms of race and ethnicity versus what our country represents. Think about the fact that over 30% of our country are from underrepresented groups and then you see that only 4% of practicing gastroenterologists are Black. I'm not sure what the number of Hispanic or Latinx is, but it's nowhere near the general population, as well as American Indian and Pacific Islanders. That's a problem because we know that there is improvement in patient satisfaction and potentially even outcomes when there's race concordance.

We know that female gastroenterologists are more sought after by female patients. We know that patients who are Black and Brown are more likely to serve in their communities or underserved communities compared to their White counterparts. So there's a huge opportunity there, but we need to include the people. If we aren't creating an environment that is inclusive and one that fosters belonging, then these issues are going to be perpetuated. I think that this kind of slow and steady, turtle-like pace move toward inclusive leadership is one way to mitigate that threat to inclusiveness. Creating more diverse teams really starts with the leader. We want to see diversity at every rung of the ladder. We want to see metrics followed and tracked, not only what the recruitment rate is but what the retention rate is. Are people leaving and why are they leaving?

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What kind of mentorship opportunities are out there? We know that Black and Brown trainees and young faculty are under-mentored compared to their White counterparts. We know the huge power that mentorship holds. All of these things need to be addressed. The minority tax and the majority subsidy are huge issues that are ongoing. Some of that work that is necessary to create more diverse teams and create more diverse groups of leaders suffers when that minority tax is so heavy, and so those are things that we need to have honest conversations about. Some people just really need to relinquish their power for others to thrive. Though diversity, equity, and inclusion (DEI) work is oftentimes confounded with health equity work, though they are separate concepts, we need to understand how much creating a diverse group of gastroenterologists can help to improve health equity.

Monica Peek:

Absolutely. Another way to diversify the team is to acknowledge gender bias in the field. Can you talk about some of the statistics in that area for us? That's for both of you.

Sophie Balzora:

I'll start by saying that there's gender bias in all areas. One of the reasons I went into gastroenterology is because there were very few women and even fewer Black women. It's been studied that, again, women want to see female gastroenterologists but it's difficult. The field is growing in terms of female representation, but when you see things like lead authorship, when you see things like Chairs of gastroenterology divisions, when you see things like social media capital and reputation, women are oftentimes on the bottom rung of things. When you think about parental leave, all of these things make it much more difficult for us to achieve what we wish to with our patients in mind and with our career development in mind. When you have those two hits against you, that intersectionality and intersectional discrimination is a really hard thing to rise above and break through, but it's part of the reason we're seeing so few female gastroenterologists, or people are hesitant to enter the field. It is definitely a huge problem that I think is worth addressing.

I'll tell you that most days that I scope, most days that I do procedures, without exaggeration, over 90% of them are women or identify as women. It's like a day of all women. There might be one male in there who snuck in, but the overwhelming majority of patients I see and particularly those that I scope, because sometimes I don't even meet them before I scope them for a screening colonoscopy, for instance, they're women. Just imagine how hard it is to find a woman. I have a lot of Black women who actually come to see me. Compared to the demographic of where I work, there's a huge percentage there. A lot of times they'll say, "I found you. I searched to find you." I hear that so often now. I'm thankful to the power of social media that people can find each other a little bit more easily, when they say, "I looked for you," and it's for various reasons, but especially for patients with IBD where women, where Black women, but even Black men are like, "We need more of you. Where are you, guys?" This is a huge problem. Nana knows this. It's a real tangible issue that we can do things to fix if it becomes more of a collective effort as opposed to just the Black and Brown people who care about it, which thankfully we're starting to see a little bit more of and hopefully we'll continue to see in the future.

Monica Peek:

Nana, do you want to talk a little bit about this leaky pipeline? It's looking very leaky.

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Nana Bernasko:

This pipeline doesn't necessarily refer to me because I'm a nurse practitioner. From my experience or from the data out there, more women actually are nurse practitioners. All kinds of women, but mostly White women, are nurse practitioners. I, as a Black woman, am a minority in this spectrum, but no more of a gender bias is not seen within my field; again, just more women as nurse practitioners. Women usually tend to be nurses and then they go into advanced training and then become nurse practitioners, but the bias here is that the Black and Brown people end up being specialists within gastroenterology. We are far and fewer in between. I'm like a gem here in this field where there are very, very few of us that do what we do.

Monica Peek:

Absolutely, and it's so important. So what's being done here, ladies?

Nana Bernasko:

We're trying.

Sophie Balzora:

I could speak to a few things. I can probably say that I'm the founding president of ABGH, which is the Association of Black Gastroenterologists and Hepatologists. I have a feeling, Monica, that the colleague of yours you mentioned is a wonderful member of our group and has helped us a lot in coming up with creative programming that not only speaks to DEI efforts, but also to help equity efforts. At the forefront of our mission is really to improve gastrointestinal (GI) health in Black communities and to promote health equity in Black communities because even when you look at digestive cancers, say one form of esophageal cancer and anal cancer, which we'll call it a GI cancer, but technically, it's up to skin. Black patients suffer the worst in all of these digestive conditions, every single one of them. Would you imagine?

That's insane. It doesn't have to be that way. It's not about genetics. There are all these other factors that we're talking about today that relate to social determinants of health. So that's at the top of our list. Ways to feed into that mission include promoting the careers of Black gastroenterologists, hepatologists, and digestive disease scientists and advancing science and promoting their scholarship that's sometimes under-recognized or difficult to achieve. We've hit the ground running since 2021 and have had some really exciting programming, and there's definitely more to come. I'm excited to say that it has really helped inspire other groups coming forward. I think that those groups are absolutely necessary. You see all of the ways that Black and Brown and other disenfranchised communities can have worse outcomes for various reasons.

Other programs that have been really fantastic in the GI space include the AGA health equity project. Dr. Sandra Quezada, who is a colleague and a friend, was kind enough to share a bit more about the AGA equity project and I'll let her share more about that because it really is fantastic, and having those specific goals and metrics is what we need to succeed and that dedicated time to do so. I've had the pleasure of being a part of the intersociety group on diversity. Unfortunately, the push was incredibly sad and with horrific events in 2020, including the very public murder of George Floyd, but it forced us to come together and collaborate as groups that have leadership

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roles in the different national societies to do something collectively. There's more power in numbers and it involves the leadership.

So again, in order to make change, you really have to involve the leadership. There's actually a study that just came out today about what people's thoughts are in the GI field from these different members of the addition, different national societies about where we are in terms of DEI and health equity and where we need to go. It's very telling, so I encourage you all to read it. It's a multisociety publication and should be easily accessible.

Monica Peek:

I'm looking forward to seeing that.

Sophie Balzora:

It's really fascinating. I will let you take a look at the results, but I'll say that it's important to know where people who may not look like you or think like you that the field is just fine and dandy and it's not, to put quite plainly. But then also, patient advocacy groups, that's really where the heart of this is. I will give homage to the Color of Crohn's & Chronic Illness, the head of which is Melodie Narain-Blackwell, who is a patient with Crohn's disease who's had it for years and years. She is a patient who is an example of a lot of the stuff we're talking about today, mainly as it relates to people not being believed or delays in diagnosis because people don't realize that certain shades can also have IBD. She has been a gift to the IBD community that's Black and Brown and really giving people a space where they can be themselves and bring that cultural element to healing.

That community has been profound. It's a really great and rich opportunity for collaborations with national society groups to learn about what patient perspectives are that are oftentimes not getting the attention they deserve. That's a mouthful, but those are the things that are happening right now.

Monica Peek:

Wonderful. What a blessing you both have been to me today. When I said, "What's going on, ladies?" I didn't expect you to say, "Well, I've started my own organization." You know what I'm saying? What a wonderful conversation. I've learned so much. I've been so inspired by you both. Thank you so much for your brilliant insight and for sharing space with me today. What an honor. Thank you, ladies.

Nana Bernasko:

Thank you.

Sophie Balzora:

Thank you.

Monica Peek:

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I'm going to put today's conversation into actions that we can all do to provide more equitable IBD care, and then I'm going to let you see if I've missed anything. So first, we can all recognize that disparities exist for patients of color with IBD, such as delayed diagnosis due to social determinants of health, medical mistrust, and limited access to newer therapies. We can identify social barriers that can lead to increased burden of disease. We can screen patients for social determinants of health. We can develop a team approach to address social determinants of health and provide more holistic IBD care. We can implement training for all health care team members regarding diversity, inclusion, and unconscious bias. Then lastly, we can work to create diverse teams of care providers.

Monica Peek:

I would like to thank Sophie and Nana once again for joining me today and to remind our audience that you can join me here for more CMEO podcasts, live webinars, case discussions, and more, including an upcoming CMEO BriefCase in IBD care. You can find out about all the upcoming live events and view previous ones on the D&I hub at the link shown here (<https://www.cmeoutfitters.com/diversity-and-inclusion-hub/>). Here are just some of the topics that we have covered so far, and we'll be adding new content every month. Please remember to collect credit for this activity by using the apply for credit button that's on your screen. Again, thank you so much, Sophie and Nana, for your input today and thank you to our audience for all of your work in providing equitable and holistic care to all patients around the globe.

Nana Bernasko:

Thank you, Monica.

Sophie Balzora:

Thank you.