

Transcript Details

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Managing IBD Care for Diverse Patient Populations: Part 1

Announcer:

You're listening to *Crohn's and Colitis Foundation Perspectives* on ReachMD. This activity is supported by an independent educational grant from Bristol Myers Squibb. Before beginning, please be sure to review the disclosure statements as well as the learning objectives.

And now, here's Dr. Lisa B. Malter.

Dr. Malter:

As the landscape of IBD patients is changing, it's important for healthcare professionals to be aware of the diversity in patient populations, and how to best serve them. We will begin by discussing the changing demographic of IBD in diverse patient populations, and then hear directly from patients regarding their experiences as they have been impacted by inequities in their IBD journey. We'll be able to then discuss disparities in care and how to bridge those gaps. We would like to note that we're aware each patient's experience through diagnosis and treatment is unique, and these two experiences are just two examples of two lived experiences. We hope that they can provide value to you as you hear the patient's story, and encourage you to ask the question, "As a result of hearing these two stories and a patient perspective, how can I look to improve my clinical practice? What tools can I use to communicate effectively with diverse patient populations?"

So in addition, please be sure to tune in for the next webinar as part of this series. We will be sharing discussions on how to apply the principles in a multidisciplinary fashion to your clinical practice. I'm gonna review our learning objectives for today's webinar. We want to leverage current case studies, research results, and Crohn's and Colitis Foundation Resources to demonstrate the diversity of the IBD patient population. We want to explain current disparities in patient care, and methods in which healthcare professionals can work through these known disparities. We want to identify differences in patient disease perception and self-management within IBD patient populations.

And we want to describe and discredit current myths about inflammatory bowel disease related to certain patient populations such as black and African American, Hispanic, Latino, Asian and the Ashkenazi Jewish patient population.

Roughly 3.9 million females and 3 million males are living in the world with IBD currently. Historically, this is a disease of wealthy countries, and this may be related to urbanization, the hygiene theory, environmental factors and dietary factors. However, we must also consider greater access to diagnostic testing and more health literacy in these parts of the world. It's also important to be aware that prevalence continues to increase, gain overall improved survival in IBD, as well as overall improved survival in all chronic illnesses. And the prevalence in incidents are increasing in historically low regions of the world.

Taking a look at prevalence changes, from 1990 to 2017, we see across the world this map that is color-coded, where the negative changes in prevalence are in the blue, cooler colors and you see positive changes in percentage in the warmer colors, and you see areas of Central America and Africa and Southeast Asia with increasing numbers during this period. Taking a look at a U.S. patient population, obviously an older one when you look at Medicare beneficiaries specifically over a 17-year period in the early 2000s, we see that both there is an increase overall in inflammatory bowel disease – both Crohn's disease and ulcerative colitis, but as you'll see, it is increasing across all of these different racial groups. Looking at Latin America and the Caribbean specifically, this comes from a nice review article from Paolo Kotze out of Brazil, and you see that over time, the incidence of both Crohn's disease and ulcerative colitis is

increasing between 1980 and 2015. Lastly, looking at some data out of Asia by Dr. Yin Su, we see that incidence map, IBD in 13 Asian-Pacific countries or regions between 2011 and 2013, and you see that there is an increase in incidence of both ulcerative colitis and Crohn's disease.

So there are some theories regarding the change of epidemiology and IBD that are being observed. This may be related to environmental changes, increased awareness both from the patient side as well as the clinician side, improved access to care, as well as the development of surveillance systems in parts of the world that historically have not seen IBD before. Some patterns that have been observed in regard to IBD is that there is a higher risk of IBD amongst second versus first generation, and younger versus older immigrants, when moving from a low to a high incidence country. Second, this shift has taken place rather quickly – over the past 10 or so years, we've seen all of these changes to the incidence and population of our IBD patients, and find that there is some nongenetic and gene environmental interactions that are at play, with regard to the pathophysiology of IBD in this group, so not just genes alone.

And lastly, epidemiologic data in inception countries is reduced relative to that available from high incidence countries, due to disparities in care, which then result in lack of underestimation of cases and lack of resources to accurately document and track the IBD that is present in that part of the world.

There are some environmental factors that we know impact IBD. The prevalence of IBD seems to increase in patients that immigrate to a country that has a higher prevalence of the disease. Western diets that are high in sugar and fat, and lower in fruit and vegetables, are associated with the development of IBD. Areas of Latin America and the Caribbean that are more industrialized are noted to have higher rates of IBD. Again, this may be related to diet, but also can't cleanly assess whether access to care and health literacy are at play here. It's also important to be aware that Hispanic patients that have moved to Miami, and then subsequently developed IBD, had reported changing their diet to a more Western one, prior to their diagnosis of inflammatory bowel disease. And varying health behaviors amongst different racial and ethnic groups may have an impact on disease course and outcome. This can include things like smoking – certain races and ethnic groups are more likely to be smokers than others – and antibiotic exposure. Of course, we see this more commonly in wealthy parts of the world, but also in other parts of the world, there could be greater access to antibiotics that are not requiring prescriptions, and patients have ability to access and take antibiotics potentially unnecessarily. So, these are gonna be hard to tease out, but important trends to be aware of in trying to understand the changing demographic, and how to best meet the needs of the changing patient population.

So taking a look at the current state of affairs, what we know about IBD to date. So, with regard to Crohn's disease and ulcerative colitis, there is some data looking at specific racial groups – Black, Hispanic and Asian – in this paper by Florence Odumbe Obi that was recently published in Current Opinions in Gastroenterology. And this is a really nice table that compiles all of the information that we have. So, in black patients and Crohn's disease, we tend to see a higher portion of patients that are presenting with penetrating disease. And a smaller proportion, in contrast, that have limited ileal or non-penetrating disease. Additionally, there seems to be a higher incidence of perianal Crohn's disease in this patient group. In Hispanic patients in Crohn's disease, we tend to see similar behavior compared to a Caucasian cohort, however there seems to be a reduced upper gastrointestinal disease in our Hispanic patient population. And, Asians with Crohn's disease tend to have a larger proportion of isolated upper gastrointestinal involvement, relative to a Caucasian. In ulcerative colitis, we have less data available to us, but we do have some data suggesting that there are lower rates of proctitis in black patient populations.

When looking at extraintestinal manifestations, this is a really popular topic, in terms of how we best serve our patients, and when we pick a treatment strategy, making sure we choose one that encompasses comprehensive care, including managing the extraintestinal manifestations. So learning more about how this impacts different racial and ethnic groups can help us better serve our patients. We note that in black patients, there tends to be a higher rate of uveitis as well as arthralgias including ankylosing spondylitis or sacroiliitis. And in our Hispanic patient population, we tend to notice that there is a higher prevalence of erythema nodosum compared to a Caucasian patient population. We also do note that in terms of age of presentation older age patient populations do tend to be noted in non-white patient populations, compared to a white or Caucasian patient population. And driving factors for this may be related to genetics, environmental factors – but again, we always have to consider the social factors that may impact diagnosis or monitoring, including cultural barriers, low index of suspicion from the clinician or limited resources for making the diagnosis and initiating and managing continued care.

There are some treatment differences that have been observed, both between the medical and surgical management of our patients with inflammatory bowel disease. We have looked at patient populations that are Asian, African American and Hispanic, and single center studies have been done, as well as some larger database studies, and really most of the results are quite inconsistent. This is with regard to biologic use, immunomodulator use and response, steroids, as well as medication adherence. So there's definitely more work to be done in this space to better understand. From a surgical perspective, there's many studies that have looked at rates of surgery, with no clear appreciated trend between different racial and ethnic groups. The only one area that has been noted is that there

seems to be a worse surgical outcome in Crohn's disease for African American patients in contrast to other races.

We looked locally at our own institution at NYU, to look at healthcare utilization and outcomes in IBD, and we performed a retrospective analysis that compared a cohort of patients that were cared for in our private setting, in contrast to those that were cared for in our public hospital setting. We looked at 322 patients, roughly 50% female, 50% from each of our hospital sites, so a even group, and noted some key findings, including that patients treated in the public hospital were more likely to use our emergency room for care, relative to those that were at our private hospital. We noted that unemployed patients with inflammatory bowel disease have higher rates of surgery. We noted that Crohn's disease patients who are unemployed had higher rates of prolonged steroid use, emergency department visits, and hospitalizations compared to those that were employed. In ulcerative colitis, we noted patients that had Medicaid were more likely to be hospitalized compared to those who were uninsured, had Medicare or private insurance.

And, in ulcerative colitis patients with private insurance, we noted that they were more likely to achieve the endpoints of mucosal healing compared to those who were uninsured with Medicaid or Medicare. So taking a look into the needs of our patient population, to better understand how we can serve them best.

So I wanna start with a couple of definitions that helps even the playing field to make sure everyone understands the concepts we're gonna review. First, health equity. This is a CDC definition which is the attainment of the highest level of health for all people, and the note that we will achieve health equity when everyone has the opportunity to be as healthy as possible. Health disparity, on the other hand, is a specific difference linked with social, economic, and/or environmental disadvantages. This is a great graphic that comes from a recent review paper by Dr. Ed Barnes from UNC, looking at racial and ethnic disparities and treatment in inflammatory bowel disease specifically. And it goes through these various, kind of buckets that we could be considering when we think about the disparities in care that our patient population currently experiences. This includes environmental differences, including sociocultural and dietary differences, phenotypic differences, differences in disease perception and self-management of a condition, differences in adherence to medications or treatment plans, differences in provider decision-making, delays in diagnosis, differences in insurance coverage and cost of care, differences in access to inflammatory bowel disease specialists, and genetic differences. And this is a great springboard for a lot of discussions that are essential to have to try and optimize and equalize the care that our patients are receiving. So some key steps to help promote health equity in IBD, includes first, detecting it – creating an awareness that this even exists. Then, taking steps to understand what is causing these different disparities and what would help you get to a health equity state, and working actively to reduce.

So I want to talk about social determinants of health, and here again, another definition. Social determinants of health is kind of an umbrella term for a number of different aspects of of a person's life and that may impact their health outcomes. So this includes things like economic stability, their education level, the social and community context which they live in, their health and their health neighborhood health care and the neighborhood and a built environment in which they live. And so these are, you know, there's a lot here. There's a lot of aspects that are helping to determine how a patient does with a condition, and as they work their way through the health system. And having an awareness of the various social determinants of health on a particular patient, and then understanding their needs relative to these determinants of health is going to be essential to meeting the patient where they're at, and optimizing their care.

So, looking at some studies that have honed in on social determinants of health, we have a study that came out of Canada from Chuck Bernstein and colleagues, looking at the role of lower socioeconomic status in a cohort of about 9,000 IBD patients in Manitoba, and they looked at outcomes including hospitalization, ICU stay, high-dose steroids and death. And basically, there is a relative risk increase for patients that come from a lower socioeconomic status in all of these categories. So all of these outcomes happen more frequently in our patients that are from a lower socioeconomic status.

Health literacy in IBD has been looked at as well. First, again, to make sure everyone is clear, health literacy is the degree to which individuals have the ability to find, understand and use information and services, to inform health-related decisions and actions for themselves and others. And this is a study that comes out of Alabama, looking at about 175 patients. 135 of them are Caucasian, 40 African American, and they assessed health literacy using the newest vital signs score, where they are considered either limited or marginal or adequate. And if you look to the right, you see the breakdown, and there is this statistically significant difference, where the African American patients had greater risk of having limited or marginal health literacy relative to the Caucasian patient population. And when you break it down even further, and look at the subgroup analysis, older African American patients are at the greatest risk for having low health literacy in an IBD patient population. And this, again, is gonna be helpful for us to understand how to optimize our patient care, when we are talking to our patients and thinking about how to break down the complicated information we are going to provide them about their chronic condition, as well as our treatment strategies.

Another aspect of social determinants of health is this great study looking at food insecurity and social support on financial toxicity in IBD

patients. This was a retrospective study using the National Health Interview Survey, and evaluated the relationship between food insecurity, social supports, financial toxicity and emergency department utilization for IBD patients. So, again, some further definitions here – lots of new terminology for many of you. Food insecurity is something that's defined by the U.S. Department of Agriculture by a 10-item questionnaire using a Likert scale, and assesses patients' answers to questions – things like concern about running out of food, or cutting portions due to cost, and things of that nature. Lack of social support was defined in this study as negative response to people in the neighborhood to help each other, or count on or trust, or a question surrounding is the neighborhood close-knit, or being worried about housing cost. So all of these questions were posed and a social support score was assessed in these patients.

And then financial toxicity was defined as financial hardship due to medical bills, personal and health related financial distress, health care affordability, and medication non-adherence specifically due to cost. And what this study found was that one in eight patients with inflammatory bowel disease experiences food insecurity and lacks social support, which is then associated with financial toxicity. And this is really heartbreaking data to have, but necessary to have so that we can again try and meet our patients where they're at, and really try to optimize, especially given the changing demographics of patients impacted by inflammatory bowel disease.

Access to care is another area where there is concern about again, optimizing patient care, and so looking at a number of ambulatory care visits for a patient seems to be directly related to opportunities for health care and improving health care. And a recent study that was published in Digestive Diseases and Sciences, a few months ago, noted that compared to patients from urban settings, patients who live in rural areas had fewer outpatient visits with their gastroenterologist, had higher rates of IBD hospitalizations, as well as higher rates of emergency department visits. And this was noted to disproportionately affect black patients with inflammatory bowel disease. So, this is a takeaway in terms of educating our patients making sure our patients have routine follow-up and being aware that there can be a disconnect when it's harder to get to the clinical care setting, depending on distance jobs climate – things of that nature, and potentially trying to identify ways to bridge that gap, including the use of telehealth and other modalities.

So in order to narrow the gap in IBD with regard to social determinants of health, we want to start by assessing these in our practice. We recognize that this is something that isn't always easy to do. Patients aren't always forthcoming about it but we have to start to ask the questions in order to understand the needs of our patients. The use of patient navigators assisting with a lot of these types of assessments is really helpful which then allows the care team to focus on disease management. We do know that this does come at a cost though, and implementing these resources into clinical practice is not something that can just happen without a lot of thought, planning and resources.

Providing culturally competent care in IBD is increasingly important as well, again with the changing demographic and increasing diversity in our patient population, and this is defined as the ability of systems to provide care to patients with diverse values, beliefs, behaviors, including tailoring the health care delivery to meet the patient's social, cultural and linguistic needs.

And this diagram to the right comes from a systematic review and narrative synthesis of an ethnically diverse patient population with gastrointestinal illnesses – not just specifically an inflammatory bowel disease, but all gastrointestinal illnesses – and as you can imagine, since gastrointestinal illnesses oftentimes create symptoms that can be embarrassing, or impact patients' ability to participate fully in their lives, the themes that come up are definitely related and important to patients with inflammatory bowel disease, as much as other gastrointestinal conditions. And the areas that were noted to have impact included religion, culture, social context, language barriers and health literacy. And the themes that were presented in this narrative synthesis, that patients reported, were related to disease presentation experiences, healthcare service experiences, medication adherence experiences, psychological health experiences and sociocultural experiences. And again, just creating awareness that ethnic minority patients may experience, with regard to their gastrointestinal illness is the first step, and then again, some ideas for trying to narrow those gaps that we will be covering in this talk.

So, enhancing cultural competency in IBD – this includes things like starting by integrating cultural competency into professional development for your care team; appreciating that inflammatory bowel disease, along with other gastrointestinal illnesses, may be considered a taboo topic and therefore additional support from a clinical team, including psychosocial support, may be really critical; generating informational resources in more languages, and incorporating that patient perspective into those resources; creating awareness that, in particular our patient population, diet may be related to cultural beliefs and alteration in diet may impact social and religious gatherings for the patient; and providing interpreter services for all clinical encounters. And I'd like to highlight SAIA, which is the South Asian IBD Alliance which is a patient-clinician collaborative, looking to assist southeast Asian patients with inflammatory bowel disease by partnering with the clinicians in order to optimize care and have real discussions about the disease expectations for management, expectations for outcome and this is really a phenomenal phenomenal start to opening the discussion and providing complete support for patients from this background.

Thinking about our medications, and understanding if the medications we have are appropriate, we've already seen that different racial

and ethnic groups may have different disease presentations, so it's important to be aware that really our trials do not have diverse patient populations in them. There's been a couple of assessments of this, including a recent research letter in gastroenterology that looked at 150 trials for inflammatory bowel disease, and noted that first of all, only 20-25% of the trials reported on race, so we have no idea. They reported on gender, disease, medication, but did not even include race.

Of the trials that did include race, 90% of the trial participants were white or Caucasian, and so this tells you there is really a significant shortfall. The IBD partner study, which comes from funding with Crohn's and Colitis Foundation, looked at about 14,000 patients, and roughly 1,100 of those 14,000 participated in a clinical trial, and if you look at the race breakdown, you see that 89.4% of those patients that participated in a trial were white or Caucasian. Percentages from the other groups are very, very, very small. So there's a long way to go with trying to diversify our trials and thankfully there are some plans to aid in the recruitment of a more diverse IBD patient population sample for studies. Clinical trials historically have struggled with diversity because there can be investigator biases as we've talked about. Clinicians can make the assumption that patients from certain races or ethnic groups may not have inflammatory bowel disease. There are significant patient biases – there is history that we're all aware of in regard to trials, and trust issues, and deceit that may have been picked up and passed down, and so it can be really hard to get patients to agree to participate in a trial without spending some time talking to them about the rationale for the trial, how the trial works, and building their trust. And then, of course, access – most trials occur at large medical centers in urban locations. As we've talked about, there are access to care issues for patients that are not in an urban setting, and therefore it can be very difficult to get to a trial, and then with repeated visits required, very onerous for the patient to participate in the trial on an ongoing basis.

The FDA is aware that diversity in trials is an issue, not just in IBD, and there is a national initiative that is working to try and narrow this down. It includes enrolling patients that are relevant to the race, gender, ethnicity and age of the patients that actually have the disease in a real world setting. It includes making participation in trials somewhat less burdensome. It includes creating creative, inclusive outreach for recruitment, providing cultural competency training for trial staff, including trial sites that have diversity built right in based on their patient population, and considering resources to bridge language barriers in recruiting patients for trials. So again, I do wanna highlight the steps to help promote health equity and reduce disparities in IBD care. This includes first, detecting/asking the questions, suspecting there may be disparities, and trying to better understand what those disparities are in order to help us reduce.

In conclusion, the incidence of IBD in non-Caucasian patients is rising. Westernization and immigration are the environmental factors that seem to be driving this change. Data-driven treatment algorithms for non-Caucasian IBD patients are not currently available. We're currently borrowing from what we know, which is primarily from a Caucasian patient population. And lastly, currently outcomes do appear to be heavily related to disparities in care, cultural and language barriers, and access to diagnosis and disease detection.

We'll now hear from two IBD patients with diverse backgrounds about their experiences with their disease management and treatment. We have today here with us, Rocio and Tara and we'd love to welcome them and are so excited to hear about their stories today. Rocio, would you like to introduce yourself?

Rocio:

My name is Rocio, and I live in Orange County, California, and I have Crohn's disease. I have been a Crohn's patient for nearly 19 years. Unfortunately, for the first five years of that time, I was undiagnosed. I actually presented with fistulizing disease, and underwent a few surgeries during that time. Unbeknownst to me, fistulas are very commonly associated with Crohn's disease, but I was under the care of a physician who wasn't specialized in IBD. So, I underwent these two surgeries, a lot of complications and a lot of suffering during those first five years, until I ended up with my medical and care team who I'm with now, who was able to diagnose me almost immediately after seeing my medical records. So, unfortunately, my disease journey was much more complicated in those first five years, in large part because I didn't know what I was living with, and because I didn't have the appropriate clinicians who were able to tell me what I was going through. So since that time, I have been under, you know, a specialized IBD care team that is multidisciplinary and I have ongoing communication with my medical team, and they're able to, you know, care for me the proper way for my disease as opposed to what I went through the first five years.

Dr. Malter:

Thank you, Rocio. We really appreciate you sharing. So many of these stories are so difficult and just having a chronic illness in and of itself is difficult, but then the journey to the diagnosis and the proper management can be so difficult and so complicated, so, in terms of getting the right course and getting on a road to recovery. We thank you so much for sharing, and Tara we'd love to hear about who you are and your journey with inflammatory bowel disease.

Tara:

Thank you for having me. My name is Tara. Uh, I am in Houston, Texas. My journey started in 2009. I started getting very sick couldn't keep food down, and over time the episodes that I was having started to become more frequent and they would last longer. And so, I ended up in the emergency room, where the emergency doctor was able to diagnose my condition, but when I went to talk to my general physician, they said that they didn't believe that I had Crohn's because, you know black people did not get Crohn's. And so, as a result, you know really there was no treatment. He gave me pain medication, and that was pretty much it.

And so when I was finally able to see a GI doctor because I didn't have insurance at the time it took me longer to be able to get and seek treatment. Once I got with a GI doctor that particular doctor was not able to diagnose my condition, and so really, I was not able to be diagnosed until 2014. But once I was able to be diagnosed and start treatment things started to improve. I had to go through a series of medications before I found one that worked. Currently I am in remission. I did have a bowel resection in 2019, and so since then things have been very stable for me.

Dr. Malter:

Thank you for sharing that with us Tara. I think, you know, similar themes here unfortunate similar themes but so important to you be willing to share those with others so that both clinicians as well as patients learn from your experiences. It's such a valuable opportunity to hear you guys speak today. o, along with those shared themes Rocio, have you had previous experiences in the healthcare system where you think things could have been improved, with regard to communication shared decision-making trust and building a rapport with the clinicians and the team that's taking care of you? Can you speak to any of those themes with regard to your own experience?

Rocio:

Sure. So, I think there's always room for improvement in a lot of things, but particularly in the healthcare system and as it relates to very complicated disease like Crohn's and ulcerative colitis you know, we all present very differently. I happened to have a very different type of Crohn's than most patients, and so even symptomatically, I'm going to present differently than, kind of, the typical patient. That being said, I think from a health care perspective, you know, I think there's a lot that isn't considered, which is the human, kind of what our life is like. What we're dealing with, what we want for our future, you know, just a lot of different aspects of our life that kind of need to be taken into account you know, when getting treatment options, or getting, you know, surgical options. You know, it's all considerations that we have to live with, forever, and so, you know, I wish there was much more decision-making that was shared. You know, as I mentioned earlier in my earlier years, without being diagnosed, I didn't know anything about IBD, so I had no information to work off of. You know, I know significantly more now, and I can speak up for myself and advocate for myself, but at the time I really was just completely unaware. So I really wish there would have been more teaching from the previous physicians, to be able to explain to me, what is Crohn's disease? What is IBD? What are fistulas? I mean, there was so much that I – especially being a younger patient was just kind of ignored, and not shared with me.

So I think, you know, there's a lot of things that physicians and just the entire health care team can take into consideration. You know, even things as simple as diet, and you know, having family with you. You know, culturally sometimes there is – there is differences with patients as well, and I think that also needs to be taken into account. I mean, we are seeing our specialists for a reason, obviously for our IBD, you know, it really extends beyond just a disease. It takes over our life, so I think physicians and health care teams need to really play a full, active role in every aspect of our life, because IBD affects our whole life.

Dr. Malter:

Yes, very true, is not just a one-time medical need, and it does not just have to be limited to the intestinal tract, as we all know, but of course so, so difficult if you don't have that education or have that information being provided to you. Can I ask in your experience were any assumptions made about you based on your age, your race, ethnicity, et cetera, that you think could have been handled differently and may have impacted your outcome either medically or, you know, just the way you were even feeling about the care you were receiving?

Rocio:

I do. I mean, I think age was a big part of it. I was in my early 20's, and you know, I was seen as a young woman who, you know, there

didn't need to be that much information that was being provided to me. So yes, I do think that there were assumptions that were made in my early journey, because of my age. IBD was going to affect me for the rest of my life, and I wish that someone would have told me that very early on for a lot of reasons especially as a woman of reproductive age, and just, you know, just what my future held for me. In addition, you know, there is a lot of assumptions that were made because of ethnicity, in the sense that I am Hispanic, and there is an assumption that Hispanics eat spicy foods. I personally do not, nor does my Peruvian culture, really. And so, you know, the assumption that I'm flaring or that I'm having symptoms because as I'm eating spicy foods is completely irrelevant for me, because that's completely inaccurate. And so, you know, there was things like that, where I wish that, you know, assumptions weren't made, and more questions were asked, that people – you know, patients were able to speak up and be able to feel comfortable with the health care team and be able to share, you know, what it is we're experiencing and why it is we're experiencing. So I think, you know, there's definitely assumptions that are made, for a lot of reasons. You know, even from an insurance perspective, you know, there's been many times that I've been asked what insurance I have, and I've been privileged to have very good insurance all my life, and so I'm grateful for that, but I shouldn't be viewed as, you know, a patient with X insurance type, you know. There is no reason to associate me with an insurance. I should be treated as a human, and as an IBD patient.

Dr. Malter:

Very true and I really think it's so critical to be sharing this with our viewers. I think that there's some that don't even contemplate that these questions need to arise, but then there are also clinicians who, depending on the practice environment, may be making assumptions and just bringing them to the forefront and creating this awareness is such a valuable opportunity. So, thank you for sharing that personal experience. Tara, we'd love to hear from you now. Just in terms of these themes with regard to, you know, your experience as a patient. How could your health care experience be improved? Again, were you subject to any assumptions? I know you did mention initially there were some assumptions based on your race and the diagnosis but how did that impact, you know, your trust between you and your healthcare professional? How was decision-making handled? Were there any concerns about communication? Can you speak to any of these themes with your own experience?

Tara:

Yes, so after my doctor did say to me that you know, black people don't get Crohn's – there was no trust after that. So he's no longer my doctor. I realized I had to find a doctor who would listen to me, and so I didn't feel like, you know, if you're telling me that I don't have Crohn's, then help me figure out what it was, or what I do have. And so, I didn't feel like, you know, he was listening. I didn't feel like there was any compassion there, and so as a result, I had to seek out a new health care provider. And throughout this journey, I mean, it's very difficult because not only are you going through the physical change in your body – because I was steadily losing weight not able to keep food down – and so, you know, every doctor that I went to before I found my current doctor, it just seemed like they – I don't wanna that they didn't care, but it was almost like, well, I don't know what else to do for you. Or, you know, maybe you don't actually have anything. You know, I had a doctor ask me if I was depressed, and I thought, well, yeah I am depressed. I'm depressed because I don't know what's wrong with me and you can't tell me. And, you know, as a result, I had surgeries that I probably didn't need. I had my gall bladder taken out. I was diagnosed with several different other things, from celiac disease you know, to, like I said, having my gall bladder removed, and it was just – the emotional stress that you go through because you know that something's wrong with you, yet people aren't listening to you and you don't feel like you're understood. So I just wish that maybe that doctor had of thought about, okay, if this is what the emergency doctor said maybe there's a test that we can do – maybe I need to do this.

But instead, that wasn't even taken into consideration, and so, you know, that kind of started that long journey of being misdiagnosed until somebody finally heard me.

Dr. Malter: [40:50]

Thank you for sharing. It sounds excruciating path to have gone through all of that and, you know, I think collectively we give you so much credit for being willing to share that experience, because I'm sure it was really difficult to go through it, and I'm sure that, you know, you still it's still there for you. It doesn't ever go away. And so fantastic that you're in a better place, and a place where sharing it feels comfortable 'cause I think, you know clinicians as well as patients alike will benefit from hearing from your experience, so thank you. When you think back about your experience, with regard to your diagnosis and your treatment process what you think could have been improved along the way? You know, just with specifics regarding your diagnosis and management in the past, as well as potentially at the current time.

Tara:

Well, in the past I felt like there wasn't a strong level of communication. Um, I felt like you – I would go to the doctor, there wasn't a whole lot of explanation there wasn't a whole I didn't feel like they were looking at, you know, maybe the big picture and I say that because of the care that I'm currently under. I feel like this particular doctor looks at, you know, the big picture and I feel like I can communicate with this doctor. I feel like it's a partnership, with my doctor and I and the staff and it's not just my physician but it's the staff. And I feel like they took their time to educate me on my condition. Prior to that, I didn't feel like – you know, I didn't know anything. I didn't know how to manage Crohn's. I didn't know – you know, it took so long to figure out what I actually had, but during that time, I just felt like there was nothing, and so, you know, I started reading some things, and trying to figure out the symptoms are there, and I can see it, but I'd look at, you know, what my symptoms are. This is what it's pointing to, but you continuously – like I said, you had people that aren't listening, and so I felt like there was no partnership between me and some of the doctors that I had. And I do understand that Crohn's is hard to diagnose and there were tests that I had to fight to take. There are tests that I had to take more than once because, you know, something may not have shown up in this particular test. You know, and I had to fight to say okay, can we take the test again? And it was through doing that, that I was able to finally get the diagnosis, but I felt like there was a struggle, like I constantly had to struggle with the doctors to get them to hear me and to understand what it was I was going through.

Dr. Malter:

Thank you. So, the communication and the relationship rapport building that you have with your care team, it sounds like has been really essential to the success of your current state of your disease, and probably overall feeling in general if I had to guess. I'm – you know, again, thank you so much for sharing that. We'd love to hear Rocio, if you can share anything from your own diagnosis and treatment plan, that could be improved or could have been improved along the way similar to Tara.

Rocio:

Yes, definitely. And I'd say, you know, as I listen to Tara tell her story, there's so much that just comes back to, again, those first five years of being undiagnosed, where I was just basically being told information by my physician, as opposed to having that shared communication. And even then, it was very minimal communication, and in part, some of it was with my parents, because I was young, and it was never clear and direct. And so, you know, one of the other things that I encountered, especially after, you know, having fistulas, and undergoing fistulotomies a couple times, I went back to my physician crying, and trying to figure out what was wrong with me, and I had to beg to have him see me, and have him figure out a plan for me. And unfortunately, he didn't have one, and he very easily passed me on to another medical team which is actually who I'm with today, and I'm so glad that he did that, at least. But even then, he literally wrote a piece – a name on – on a piece of paper, and sent me on my way. You know, and then all the legwork, all the medical records, I had to do on my own, to establish with my current team. That said, you know, it's night and day to be working with a medical team that's IBD specialized, that, you know, in my first appointment with the physician, he looked at my medical records, and was very easily able to tell me that I had Crohn's, just because of my recurring fistulas. I just mentioned I had two fistulotomies, that I never should have had. I should have been under medical treatment, first, that would have killed the fistulas without me undergoing surgeries, which has now caused me significant number of complications and additional surgeries beyond that. So, you know, there's so much that really did go wrong those first five years that I wish patients don't have to go through now, and you know, I know as Tara mentioned, you know, obviously both diseases are very hard to diagnose, but I do, you know, feel that patients need to have a lot more information provided to them, to be able to understand the disease that they're living with, and then have – of course, how to live with it and how to treat it and what options there are available to them. So, you know, a lot went wrong in the first part of my journey, but, you know, a lot's going well with my current team, and I do feel like having that ongoing communication, sharing, you know, other circumstances that may be affecting our disease you know, is important so that our clinicians can understand, you know, what our bodies are going through and why we may be flaring, because of other underlying reasons.

So, you know, that communication, I think, is definitely the biggest factor to consider from a clinician to patient perspective, and vice versa.

Dr. Malter:

Thank you. Thank you both, for sharing these stories. It's been phenomenal to be able to kind of unpack your experience and really, again so fantastic that you're willing to provide your experience with clinicians who are out there taking care of patients and with the changing demographic of those afflicted by IBD. These things are going to be only increasingly more common and more important to tackle. There are a few themes that I think would be important to reflect on, at the conclusion of our program today. I think the theme of

bias has come up in both of your stories and having an open attitude about who may be afflicted by inflammatory bowel disease. Really, we can't ever say that any race or ethnicity is excluded from this disease, unfortunately. The numbers are only increasing and the diversity is only expanding, so anybody can have this condition at this time. And it's important, clearly, communication has been a theme that has come up over and over, and I think the, you know, how both of you ended your discussions and stories today was just the notion of communication, shared decision-making communication including education of you as the patient which will help you in the shared decision-making process, as well as allow you to have ownership of your disease and advocate for yourself. And so I think that we can't stress enough the need for open communication and from the get-go really.

I also noted that both of you talked about assumptions that were made about your condition or habits that you may have had, based on your racial or ethnic background that may or may not have impacted your disease, or aspects of your care, and so I think it's really important to take into account that we should drop all assumptions and again, this goes back to the communication – talk to your patients, understand their work, their life, their culture. What is impacting them that may impact their disease, or may not? In the instance that Rocio gave about not eating a diet with spicy foods, yet that assumption kept coming up in her care and was being attributed to some of her symptom profile. So, really not making assumptions, and again, this goes back to communication.

And lastly, you know, while we're really primarily speaking about two disease states - inflammatory bowel disease, ulcerative colitis and Crohn's disease – every patient has their own story, and that's why some of us as clinicians make a career of this, because there are so many different ways this disease can play out.

No two patient stories are alike, and individualizing the care for the patient, with regard to all of their care, from a comprehensive standpoint, is gonna be essential to provide the best care for the patient. So, meeting the patient where they're at, in terms of their understanding and their needs and then paying attention to each aspect of their life – asking questions if you have them and trying to provide the most comprehensive care. I think the concept of the team and feeling supported by the team approach that both of you shared is – is really great. And IBD is moving more into a multidisciplinary care place and I think that's really important, to be feeling supported not only by the primary clinician who's taking care of your disease, but all of the team members as well. I think with that I will wrap up. Again, thank you so much, Rocio and Tara, for sharing your stories with us today. And thank you for your attention to this important topic.

Rocio:

Thank you so very much for having me.

Tara:

Thank you so much for having me.

Announcer:

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