

Transcript Details

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South Asians With IBD: Underrepresented and Underappreciated

Announcer Open:

Welcome to CME on ReachMD. This activity titled, South Asians with IBD: Underrepresented and Underappreciated, is provided by Clinical Care options LLC, in partnership with the South Asian IBD Alliance, and is supported by independent educational grants from Takeda Pharmaceuticals USA Incorporated, Janssen Pharmaceutical Companies, Lilly, Bristol-Myers Squibb, and Hollister Incorporated. Prior to beginning the activity, please be sure to review the faculty and commercial support disclosure statements as well as the learning objectives.

Dr. Nandi:

Hello, and welcome to this Medical Minute, part of a three-part series from the program titled, Breaking Borders – Optimizing Care for South Asians with IBD in the Mainland and Beyond. This activity is supported by independent educational grants from Takeda Pharmaceuticals, Janssen Pharmaceuticals, Lilly, Bristol-Myers Squibb, and Hollister. I am Dr. Neil Nandi, and this first Medical Minute is titled, Patient Insights – What I Wish I Knew About Me and My IBD, presented by Madhura Balasubramaniam.

Madhura Balasubramaniam (Patient Advocate):

Thank you so much, Dr. Nandi. I'm going to share my experiences as a South Asian with IBD. And through this process, I want to highlight what are the cultural considerations that shape treatment decisions and outcomes for South Asians like myself who live with IBD, and also discuss the importance of understanding and addressing some of these factors, especially when they present as barriers to care for patients.

So, a little bit about myself. I'm a PhD student and I'm a patient advocate with South Asian IBD Alliance, SAIA. I live in India. I was diagnosed with Crohn's disease in 2019. And since then, I've had a journey with multiple complications. I presented with severe malnutrition that needed a percutaneous endoscopic gastrostomy, or PEG tube. I've struggled with a gastrocutaneous fistula from the PEG tube site, developed multiple bowel obstructions and skin extraintestinal manifestations. I have been on adalimumab since 2021. And throughout my journey, I've experienced several delays in care and struggled with several cultural barriers to accepting the disease and treatment. So, this is what I want to share with you all today. And thank you so much to everyone for being here.

So, this graphic highlights the multiple hurdles that a typical patient of South Asian origin faces. So, I want to really emphasize here that the story I share today is not my story alone; this is the experience of many, many South Asians. And these barriers delay care, and they impact outcomes and quality of lives for South Asians.

Again, I'm not the only one going through this, and that is why it is so important to pay attention to this experience.

So, one of the things that's very important to talk about when you speak about care for South Asians with IBD is the centrality of cultural stigma. And I feel like the Hindi/Urdu phrase, log kya kahenge, captures this very well. So, what is log kya kahenge? It means, what will people say? And it cautions you to be aware of social perceptions when you make a decision. It constantly reminds each one of us that what your family or what the next-door neighbor or even a complete stranger thinks about you and says about you, matters. To me, log kya kahenge encapsulates the everyday experiences of stigma that IBD patients face. Our diagnosis, our treatment decisions, acceptance of the condition are often marred by the fear that we are bringing shame upon ourselves or our families.

And cultural stigma, it's very important to note, is not just the preserve of people who are less affluent or who live in rural parts of South Asia or who live only in South Asia. This is something that affects each one of us, regardless of whether we live in urban or rural places, regardless of whether we're literate or not, regardless of socioeconomic status, and regardless of whether we're in South Asia or in the global diaspora. It serves almost like a cultural determinant that both consciously but also subtly shapes the decisions that we make as

patients. So, any attempt to deliver culturally competent care to South Asians with IBD must understand how cultural stigma shapes our diagnosis, treatment decisions that we make as patients, the decision to undergo surgery, the decision to enroll in a clinical trial, and also the psychosocial burden that we carry over and above the disease itself.

So, let's talk a little bit about the diagnosis and the role of cultural considerations in the same. Firstly, there is a low disease state awareness in the global South Asian community. So, for instance, I've had chronic diarrhea, vomiting, and weight loss since for as long as I can remember throughout my childhood. But the lack of awareness about the importance of paying attention to changes in bowel habits, what are concerning symptoms, and when to seek help, leads to delays in diagnosis. In addition, stigmatization of bowel disease is an important factor. This is something that's present in many communities, but this is especially pronounced among South Asians, where many bowel symptoms are considered taboo; you cannot talk about them with anybody.

So, the picture on the right was taken 1 week after I suffered from my first episode of fecal incontinence as an adult. And I was so ashamed of that experience that I didn't tell anyone; I pretended it never happened. Finally, it was my rapid weight loss that made my mother drag me to a doctor and led to my diagnosis. I could not even talk to my mother about what I was going through. Together, these factors meant that it took me over 20 years to be diagnosed from when my first symptoms began.

The diagnosis journey is one aspect of it. The cultural considerations when it comes to treatment decisions is a whole other aspect, and it's a long journey.

There are three myths or deeply rooted misconceptions about IBD within the South Asian community. Firstly, the idea that IBD is caused by the patient, by the patient's poor diet or lifestyle. This implies that if you correct your diet or lifestyle, you can cure yourself. The second, the idea that long-term medication use is bad, because IBD medications are not safe, there are many dangerous side effects, and it creates dependency. This is a very common perception among South Asians. And it's important to note here that these fears are rooted in a historical experience of colonialism. Evidence-based medication was introduced in South Asia at the advent of British colonialism. So, this is a long and traumatic period of South Asians, and it shapes our decisions to the day. The third very important factor is the belief and faith in complementary and alternative therapies. It's believed they're safer and that they can cure your disease. And this is part of cultural heritage for South Asians as well. Together, these misconceptions contribute to delays in adoption of IBD therapies, complications, and poorer outcomes.

So, like many South Asians, I also internalized this belief and I started to restrict my diet. So, I removed entire food groups, believing that these were trigger foods and that removing them would help me feel better. I was convinced that with the diet changes that I was making and the mesalamine that I had been prescribed, that in 6 months I would be back to normal, whatever normal meant at that time. Six months later, I was severely malnourished; I was down to 74 pounds, and the disease was ravaging my body, causing me to develop pyoderma gangrenosum on my shins. I was also wracked with the guilt, because I was forced to contend with the decision that I might need to start a biologic. And I felt like I had failed my body. I was terrified of what it meant to start a biologic and the associated side effects, because in the South Asian community, a biologic is considered a last-resort treatment. And I felt like maybe I wasn't sick enough to need a biologic; maybe I could try to change my diet a little bit more.

It would take me another year and multiple conversations with my amazing IBD specialist to change my view on a biologic, to view it not as a last-resort option, but as an effective option that would give me greater quality of life and give me my life back. But this delay meant that I suffered multiple complications along the way.

This is something I really want to emphasize. It is important to remember that when a South Asian IBD patient makes a decision, it is not an individual decision. Decisions are often family decisions, and recommendations from the family and from social circles are often very central to the final decision a patient makes. So, for instance, my mother and I faced so much resistance when a feeding tube was offered to me. Most of my family thought this was completely unnecessary, especially when complementary and alternative therapies, like aloe vera, 08:51 promised a cure. Why would you want a feeding tube when you could be cured by this – cured of this disease? To avoid the constant judgment, we didn't tell anyone I had the tube placed until after I came back home from the hospital. Going up against your loved ones in quite this way is an incredibly isolating and an incredibly difficult decision to make and a decision to live with as well. And when we speak of shared decision-making, we must be cognizant of this factor, and healthcare providers must be empathetic to the challenges that South Asian IBD patients make. We have to find ways to account for the central role that families play in decision-making for South Asian IBD patients.

So, let's turn our attention to clinical trials now. In December of 2021, I started to lose response to adalimumab. And I was faced with the question of what next. In India at that time, we did not have access to a different therapy that had a different mechanism of action, and to date, it isn't necessarily easily accessible. So, because of this, clinical trials appeared on my horizon. But like other South Asians, I faced multiple factors that prevented me from participating in a trial. Firstly, the medical mistrust in the community is compounded in the context of clinical research, there is a fear of being experimented upon, and this runs deep. Secondly, there's a massive knowledge gap

about the safety of trials and how to access a trial to begin with. Thirdly, the communication around trials. For many of us, clinical trials are often presented in the face of aggressive disease and limited treatment options. And this reinforces the message that a trial is a last resort and not a part of the treatment toolkit. And finally, family. So, even though I was keen to participate in a clinical trial, I could not even broach the topic with my family because I was afraid they would say no. So, family education is key, especially when you're talking about South Asians with IBD. And I believe that some of these factors need to be addressed if you want greater representation and greater diversity in our IBD clinical trials.

And to talk a little bit about surgery as well, there is a deep perception that surgery is truly a last-resort option. Ostomy surgery, in particular, is considered absolutely unthinkable; it is considered the end of your life. And there is intense stigma, and it really breaks my heart to say that South Asian ostomates are ostracized from the community. They're prevented from entering places of worship, they're prevented from entering their own kitchens because ostomies are considered impure. In South Asia, there is also a dearth of colorectal surgeons. And these factors together limit the use of surgery as a treatment option, it leads to complications, and it leads to poorer outcome due to the delayed uptake of surgery.

Apart from the debilitating symptoms of IBD, I also bear the additional burden of negotiating some of the psychosocial factors of being a South Asian with this disease. There is just so much blame placed on IBD patients for their diagnosis, you must have eaten wrong, it's your bad karma. And there is so much blame placed on you for needing a treatment option like a biologic. Secondly, there is just so much negative perceptions that are associated with IBD, but also, chronic illness more generally in the South Asian community. Patients are considered to be not fit for marriage and not fit for parenthood.

So, a few months back, I walked into this conversation with some of the elders in my family. And they had very casually written me off from ever getting married. And this is what they said, 'How can we place your disease and that burden on someone else? It's not fair to the other person.' I think this creates so much pressure to hide your diagnosis and to present as being well, to avoid this constant scrutiny and constant judgment from everyone near and dear to you. And this leads to increased social isolation. It is also so challenging to discuss these concerns with your physicians, because we don't want to speak ill of our families. And it's also important to remember that this speaking ill of your families may come at an additional cost and with social repercussions for patients as well. So, as a result, these barriers may not be immediately apparent to the clinicians who are treating us, and it may appear that we are being difficult or willfully choosing to ignore medical advice. The reality is, we're struggling to even ask for help.

So, this presents a unique cultural terrain. And this necessitates a unique cultural intervention that addresses patient and community education, cultural competence in IBD care with new models of shared decision-making. And we need culturally competent research initiatives that are sensitive to the challenges of South Asians with IBD. And it's precisely this multipronged approach that SAIA takes as well. And we, as Dr. Nandi said as well, are a patient-clinician collaborative that aims to empower every single South Asian IBD patient of South Asian origin. We want to create resources, research, and education, both for patients but also for clinicians treating these patients to minimize disparities, to improve and promote early diagnosis, to dispel the stigma, and improve access to care and to enable our South Asians with IBD to live fuller and happier lives.

And with this, I want to say thank you for your attention, and I'm going to turn over to the assessment question.

Dr. Nandi:

The answer is B: Cultural belief in the South Asian community that IBD can be cured by diet changes and lifestyle interventions.

Madhura Balasubramanian (Patient Advocate):

The answer is: Cultural belief that IBD can be cured by diet changes, prevents many of us, including myself, from exploring IBD medications as a first-line treatment and it contributes to delays in adopting IBD medication.

Dr. Nandi:

Thank you for participating in this activity. And please remember to view the other Medical Minutes in this series. To earn CME or CE credit for this activity, please click the 'claim credit' button below. Thank you.

Announcer Close:

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