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# Examining the Lifetime Impact of a 25-Year Misdiagnosis – Part 2

**Announcer:**
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**Dr. Iroku:**
Hello, my name is Dr. Ugo Iroku. I'm a Clinical Assistant Professor at Mount Sinai Hospital, and it's my pleasure to introduce to you Dr. Ayanna Lewis.

**Dr. Lewis:**
Hello, thank you so much for the kind introduction. I am Dr. Ayanna Lewis. I am an Assistant Professor of Medicine at the Mount Sinai Health System based at Mount Sinai West and Morningside. I'm so glad to join you guys today.

**Dr. Iroku:**
So, Dr. Lewis, we have an interesting patient case that we're going to dissect today. Patient X, as we'll call him, who's an IBD advocate, of course, an IBD patient himself, who's gracious enough to share his story with us. So, it sounds like he is a gentleman in his mid 30s, who was doing fine in life up until the age mid 30s in early 2009, when he developed severe abdominal pain, weight loss, and really didn't have a reason to explain these symptoms. There was nothing he'd experienced earlier in his life at all.

He approached his gastroenterologist, had multiple conversations about his pain. He felt his gastroenterologist really wasn't understanding what he was going through. There were some initial tests done, some bloodwork, eventually proceeding to getting sonogram and even an endoscopy and colonoscopy, but it just showed gastritis and really not much was shown in the colon. And ultimately, his symptoms became so severe that he was put on a number of medications, anti-reflux medications and even SSRIs with no improvement. And ultimately, his symptoms progressed to the point where he did have to present to the hospital with severe pain, with severe anemia at the time, received two blood transfusions, saw a different gastroenterologist, and was eventually diagnosed with having Crohn's disease of the ileum based on a video capsule endoscopy findings.

So, I want to start off with his initial presentation. Is that something you've seen much of, where people are presenting to the gastroenterologist or their primary care doctors and not finding an answer? And what are some of the things that the lay public and then also our primary care doctors and gastroenterologists should be thinking to help make a quick diagnosis of Crohn's or ulcerative colitis?

**Dr. Lewis:**
So, unfortunately, patients with inflammatory bowel disease often find that they're in these sorts of situations where they have symptoms for a while and no one really quite knows what's going on. I think part of it is we're having an emergence of Crohn's and ulcerative colitis in groups that we hadn't necessarily seen these conditions before. And so sometimes, if patients don't fit the typical picture, people don't think of these conditions upfront. And that's why it's important that if you're not getting the answers that you want, that you advocate for yourself and look for those answers with other physicians, if necessary.

**Dr. Iroku:**
And so, a lot of our providers may say, 'Well, he wasn't having bloody stools, he wasn't having diarrhea.' Do we see that with Crohn's disease where they just present with abdominal pain and weight loss like this patient did?

**Dr. Lewis:**
I would say yes. You know, with these patients, the symptoms can vary significantly. So, patients can have pain, they can have diarrhea, they can have weight loss. Sometimes they can be asymptomatic and still have active disease. And particularly with patients with Crohn's, there can be a discordance in terms of the amount of active disease they have and what their symptoms show. And so, it's really important if there are signs that something is going on, that a thorough investigation is undertaken.

**Dr. Iroku:**
Exactly. And without that inflammation in the colon, like in his case with it just being ileitis, it may not be too atypical to present with just pain and sometimes bowel obstruction and not the usual diarrhea and bloody stools that some patients are used to reporting that catches the providers ears, right.

**Dr. Lewis:**
So, everything too is the duration of their disease. If you're catching someone early in the disease versus someone with much more advanced disease, the presentation may differ.

**Dr. Iroku:**
So, in his case, he eventually saw his second gastroenterologist who did the video capsule endoscopy that did show presence of inflammation in the small intestine. He had a repeat colonoscopy with deeper intubation into the terminal ileum that, on second attempt, that, you know, with the second gastroenterologist did in fact show inflammation of the terminal ileum higher up than the prior gastroenterologist had seen on his first examination. And so, the disease was diagnosed, he had Crohn's ileitis. And then comes a conversation of what medications to put the patient on.

So, when you're seeing that person who's just been diagnosed with Crohn's ileitis or otherwise, what are some of the first things that are coming into your mind that make you decide what are the best treatment matches a person can be on to match their disease presentation?

**Dr. Lewis:**
So, I think whenever I think about patients, a few things come to mind. So, one is the severity of their disease. So, someone who has very mild disease, I'm not looking to put them on heavy immunosuppression. But when people present with severe disease, it's important that we match the level of their disease with the medications that we choose. And fortunately, we're in a time where there are a lot of options in terms of biologic therapies and small molecule therapies that can be used to treat inflammatory bowel disease that weren't an option before.

The other thing that matters, too, is patient adherence, right? No medication works if a patient doesn't take it. And so, when you have a patient who is thinking about therapy, and also thinking about their life, they want to make sure that it's something that they can obtain on a regular basis. And also, be consistent with because, again, these medications work if the patients take them.

And then the last thing that usually comes to mind is, of course, coverage with insurance companies, which is always an issue. I think it's important that patients be with physicians who are willing to fight for them to get the right medications upfront. Because we know that the first biologic agent that a patient's put on is usually their best biologic agent, and they have the best response to it. And so, it's important that when we make that first decision, that we make a good one, not thinking of the patient just in the moment, but the patient for years to come.

**Dr. Iroku:**
Excellent, excellent answer. So, his second gastroenterologist made the decision that patient X would be a perfect fit for an anti-TNF agent. Only one problem, the patient didn't want to be on it. And so, they had a conversation. And ultimately, the gastroenterologist, sensing that really the patient did not buy into jumping into an infusion or a self-injection with an anti-TNF just yet, they had an agreement that they would try mesalamine oral therapy, and give it almost a full year of trial. And of course, if he had a severe flare, he could jump to something stronger, but otherwise, give it the full year. And then at that point, agree that if there was still inflammation going on in the gut, that they would bump up to a stronger medication. Do you agree with this approach or disagree with it?

**Dr. Lewis:**
You know, it's tough because anytime that you're making a decision about a medical problem that's affecting a patient, it has to be shared decision, right? We have to include the patient's wishes, desires, thoughts, and concerns about side effects. All of those things

are really critical in making the decision.

In terms of the mesalamine therapy, we pretty much know that it's not the best therapy for treating Crohn's disease. But one thing that mesalamine does offer is ease of use. So, I can understand why this medication was chosen. Would it have been my first-line option as an alternative to a TNF? Probably not. But I think sometimes you're forced to make tough decisions when patients are resistant to, you know, being on stronger medications because of whatever reasons.

**Dr. Iroku:**
And in fairness to the situation, this was over a decade ago at this point, and so the wonderful, amazing options we have today weren't necessarily easily accessible back then.

But lo and behold, a year passes. He does fine in terms of his symptoms, but like you said, just because he's feeling fine, it didn't mean that he was in clinical or endoscopic remission. And when they took a look, a year later, he had a significant amount of inflammation. And at that point, put him on an anti-TNF.

These days, other than the option of an anti-TNF, what are some other classes of treatments that you consider putting your patients on? And what kind of feedback are you getting from your patients when you have those conversations with them?

**Dr. Lewis:**
Well, I mean, as I mentioned before, there are a lot more options. So, in terms of classes, he was offered the anti-TNF, which was one of the first classes that were available for treating Crohn's disease. Now we also have anti-integrin therapies as well as anti-interleukin therapies. And these classes of medications can be given in various ways.

Other options to consider are the small molecules. So, newer medications that act on the JAK-STAT pathway have been significantly efficacious in treating patients with Crohn's disease.

And so, all of these options allow for us to have much more choice about how we deliver medication, whether it be by pill, injectable, infusion, etc. And so, patients really do have more options in terms of picking a choice that fits in their life.

**Dr. Iroku:**
Thanks for that amazing survey of our treatment options that we have to offer our patients today, Dr. Lewis. And thank you for joining us. Take care.

**Dr. Lewis:**
Take care.

**Announcer:**
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