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ReachMD
www.reachmd.com
info@reachmd.com
(866) 423-7849

Investigating the Impact of Stigma on Patients with IBS

Dr. Buch:
It's an unfortunate reality that many of our patients with irritable bowel syndrome, a disorder of the gut-brain interaction, face stigma from family, friends, coworkers and sometimes even clinicians. So what do we need to know about the impact of stigma on our patients, and how can we all work together to reduce behavior? Welcome to *GI Insights* on ReachMD. I'm Dr. Peter Buch, and joining me in this unique, patient-centered discussion about stigma is Dr. Douglas Drossman and his patient, Ms. Johannah Ruddy. Dr. Drossman is Professor Emeritus of Medicine and Psychiatry at the University of North Carolina, and president of the Rome Foundation. Dr. Drossman, thanks for being here today.

Dr. Drossman:
Thank you for having me.

Dr. Buch:
And not only is Ms. Johannah Ruddy one of Dr. Drossman's patients, but she's also the Executive Director of the Rome Foundation. Ms. Ruddy, it's great to have you with us today.

Ms. Ruddy:
Thanks so much for having me.

Dr. Buch:
So, let's get started with you, Ms. Ruddy. As a patient with IBS, what stigmas have you faced, and how has this impacted you?

Ms. Ruddy:
Well, thanks for asking that question. I think there's different types of stigma. And so I think it's first important to understand those types, because they can all be experienced in different ways and have different impacts on patients. So, there's perceived stigma. There's enacted stigma, and then there's what's referred to as internalized stigma. Perceived stigma is really referring to a patient's experience of being treated negatively in response to their condition, or their attributes. Enacted stigma is more looking at behaviors that are discriminatory based upon the individual's attribute, and then finally the internalized stigma, which is really the most impactful is when a patient begins to align, or believe those negative stereotypes that are put on them, due to their condition, and that can have the most profound impact. For me, I really struggled mostly with that perceived stigma, coming mostly from my clinical experiences with physicians that I thought trying to find care for my DGBI. Because they were seeing them as not legitimate there was no structural cause for them, so in their mind, there was no legitimate diagnosis or way to manage them, so they made it – made me feel like they were mostly stress-induced conditions or symptoms, that they were even psychologic – that I was maybe making them up, or I was somehow contributing to them myself, within my actions or my behaviors. And so I really started to doubt myself after awhile and start to believe that perceived stigma that maybe I was making – maybe it wasn't as bad. Maybe I was crazy, maybe it was the stress of my life that was causing this, and maybe I should just stop seeking health care and just learn to deal with it. So that really started to drive the negative mental health behaviors, and hypervigilance, and symptom-related anxiety and depression as well. So, I think it's important to understand, clinically speaking, that stigma can be very, very damaging to patients, particularly patients with chronic illness.

Dr. Buch:
Thank you. Turning to you now, Dr. Drossman, what goes through some providers' minds when they're about to see yet another patient with "functional illness?"

Dr. Drossman:

Well, that's where the stigma can come in a typical response could be something like, "Oh, no. Here we go again. How long is this gonna take?" And the issue that really comes up is that in general, with our society is that patients with disorders of gut-brain interaction are considered second class. It's not easy to diagnose unless you use the Rome criteria, and it may be associated with difficulties in management, and as a result, doctors may treat patients in a way that's very different. And looking for the more simple fix, someone coming in with GERD that they could put on a PPI, rather than someone who's had years of chronic abdominal pain or bowel dysfunction.

Dr. Buch:
And as a follow-up to that, what would you say to that busy provider who is obliged to see patients who suffer from disorders of gut-brain interaction, but who are angry or upset by these patients?

Dr. Drossman:
Well, first of all, we have to understand why they're angry and upset. Is it because the interaction, the communication, is not going well, or they don't believe in the diagnosis? You know, the use of the Rome criteria can legitimize these conditions. Or is it something about their perception that they're not doing a good job? If the patient's not getting better, then possibly you need to refocus and begin to say we have to work together on establishing a better mode of operation. Doctors sometimes get a hypertrophied sense of responsibility, where they feel that their job is to come up with a diagnosis and come up with a cure or the treatment, and then the expectation is that the patient will get better and will thank them for it. But that doesn't happen very often, and then what that can lead, are difficulties in the way the doctor sees his or her view of their role. They may feel that they're failing, and a simple response is to get angry. Now, you have to realize that it was Paul Valéry who talked about when he was talking about art that when you see a person, you have to see them for their own worth and value. Don't pre-judge it. So if you pre-judge based on prior experiences, or because the patient has a DGBI, that they're gonna be more difficult or more challenging, well you're walking into that visit in a bad footing. But if you take each new visit as a new experience, generally you can make it through with a lot more satisfaction.

Dr. Buch:
Thank you. For those just tuning in, you're listening to *GI Insights* on ReachMD. I'm Dr. Peter Buch and today I'm speaking with Dr. Douglas Drossman, and his patient, Ms. Johannah Ruddy, about the importance of addressing the stigma that often surrounds disorders of the gut-brain interaction. So Ms. Ruddy, from your perspective as a patient, why is it important to address stigmatization?

Ms. Ruddy:
Well, I mean, stigmatization drives symptom severity, it drives healthcare utilization rates. It drives what Dr. Drossman refers to as this vicious cycle of patients going to the doctor being hypervigilant and having selective attention on their symptoms which then is making their symptoms worse, exacerbating those. They are getting worked up, but nothing shows up on the tests, and so they leave feeling frustrated, which then has illness-related anxiety that, again, just goes in this circular motion with no real end results and finalization of how to help these patients. So, it's really important, I think that from a clinical standpoint that the doctor is not contributing to any kind of stigmatization with the patient, that they're providing reassurance and education that these are legitimate conditions, that they have a pathophysiology, that there are appropriate treatment methods available for them, but that we do understand they are disorders of gut-brain interaction, and so there may be some component of them that can benefit from a GI health perspective, whether that's through health psychology, whether that's through the use of what used to be called anti-depressants, now called neuromodulators. So all of that education and communication with the patient will reduce the stigma that they're feeling or that they may have experienced from other providers, help them to accept the diagnosis and the treatment plan, and then help them move forward with a better quality of life.

Dr. Buch:
And Mrs. Ruddy what advice would you share with patients who are now listening, who feel stigmatized by their providers?

Ms. Ruddy:
I talk to a lot of patients as a patient advocate who are feeling these same sorts of behaviors and feeling very stigmatized by their physicians feeling dismissed and not heard or understood. And I think first of all, I always acknowledge to them that those negative comments are always hurtful, and so acknowledging that, but also acknowledging that there's things they can do to try and change that. So, when you're seeing a doctor, and the doctor's kind of attributing all of your symptoms to your behaviors or to maybe a mental health condition, you can really use your self-advocacy skills to dig a little bit deeper into what's driving that behavior and those messages from your doctor. You know, a lot of times, they're not trying to be hurtful. They're just maybe lacking in the knowledge of what to do for you, as Dr. Drossman mentioned earlier. And so, I encourage patients to kind of challenge that a little bit, and just say, you know, something to the effect of, you know, "Dr. Blah-Blah, when you say that my condition is – is all due to stress I'm not hearing from you a real medical diagnosis, or a plan to manage it. So can we clarify that and can you clarify for me what it is you're saying?" And when you start to kind of challenge that, and dig a little bit deeper, and have a more patient-centered conversation, that can – that sometimes can really help to turn things around, and you can start to realize that the doctor wasn't intentfully trying to stigmatize you. It was just the lack of

knowledge. But I would say to patients that if you've done that and you've done the self-advocacy component, if the doctor is still seeming to be dismissive or argumentative you could probably at that point, reconsider your choice of physician. And the reason for that is that patients with DGBI, they need a partner in their care, and if the doctor is not going to be your partner, and provide legitimacy to your diagnosis, and work with you as a partner in your treatment plan, you're gonna know that pretty early on. And if that's not something that you think is gonna be a reasonable request for them, and that you feel comfortable working with them on, then it is okay to find someone who can do that with you and for you.

Dr. Buch:
Thank you. And Dr. Drossman, I'll give you the final word. How can patient-centered care help to reduce the stigmatization of disorders of the gut-brain interaction in our patients?

Dr. Drossman:
You know, I think if we're talking about stigma, we have to start to take a step back and say, "Why is there stigmatization of patients with DGBI?" It doesn't happen with other structural disorders. And I think what we're seeing is that in medicine, we learn about pathology and structure, and there's a certain value to knowing that, so we have a diagnosis. But with the DGBIs, there are no structural abnormalities, and sometimes doctors get lost about what's wrong or what to do. I recall one time, I was giving grand rounds in in New York. Actually I went to residents' report, and they presented to me a case of a patient with unexplained abdominal pain, that went on for years. And as the resident presented it, he started to say, "You know, I just don't like this patient. I don't want to see her anymore. She's driving me crazy." And I said, "Well, what if, on the next visit, the patient came up and you made a diagnosis of pancreatic cancer? Would that make a difference?" And everybody looked around and shook their head yes, and the doctor said-- the resident said, "Well at least I have something to work with." And the message there, although the patient would surely die, was that the concept of having a structural abnormality gives certain credibility to what the doctor is doing. And I think that when doctors don't have a clear diagnosis, if they don't believe in the use of the Rome criteria or the positive diagnosis, it goes back to that survey I talked about before, where they don't have a diagnosis. And sometimes they can turn that on the patient, because their own feelings of not being able to handle the problem can be turned off, and they can blame the patient. So, stigmatization is something that we have to deal with by understanding the validity of it. You know, it really goes back, about three centuries ago, when all of medicine became pathologically based, in the 1700's. Up until that time, there was no good way to diagnose the patients, through surgery or through autopsy, but when Descartes came up with the concept of mind-body dualism, the brain, the mind was separated from the body, and the church, which had forbidden surgery because the spirit was in the body, now said the spirit is outside the body, let's allow surgery and autopsy. That led to pathology, and pathology led to histopathology and radiology imaging and MRIs, and all of medicine became structurally based. But back then, when patients had behaviors that weren't structurally based, they had behaviors that they thought was possession. And later, insanity. And that concept of behaviors not having a structural basis, has permeated for 350 years. In fact, mental health didn't even get into the medical curriculum until the turn of the 20th century. So that is what led to the stigmatization, because it wasn't felt as valid as a structural diagnosis. And that's what we're trying to change by understanding brain-gut interactions.

Dr. Buch:
So how do we help correct this by talking about patient-centered care to reduce the stigmatization of these DGBI patients?

Dr. Drossman:
First, we don't have to take the responsibility to always diagnose a structural finding. We legitimize their symptoms, their illness. The illness is the patient's perception of ill health. Disease is pathology, and even though we would like it all to be pathologically-based, so we can fix it, the reality is a lot of pathologically-based conditions we can't fix. But the patient's experience of ill health, which is a whole biopsychosocial construct, can be dealt with through good communication, valuing the patient, legitimizing their symptoms, providing a sense of trust, and working together on the treatment. So then, the responsibility is shared and the patient will get better. But patients don't necessarily need to be cured. When they have a chronic illness, they know it, but they want someone who won't abandon them with their symptoms.

Dr. Buch:
Well those are great thoughts for us to keep in mind, and I want to thank you, Ms. Ruddy, for sharing your perspective, and Dr. Drossman, thank you for offering your expertise as well. It was great speaking with both of you today.

Dr. Drossman:
Thank you.

Ms. Ruddy:
Yes, thanks for having us.