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Intimacy & IBD: Addressing Common Challenges & Concerns

Ms. Rubin:

Today I have with me Ashley Perkovich from the University of Chicago who is joining me to discuss intimacy and inflammatory bowel diseases

Ms. Rubin:

Ashley, why don't we start with discussing the issues that are involved in intimacy and IBD?

Ms. Perkovich:

Thanks for asking that question, Michele. As you know, there are many factors that contribute to intimacy issues in IBD, such as not feeling well or losing the urge, certain medication side effects such as fatigue, the loss or the fear of the loss of control of bowel function, fecal incontinence, impairment of body image and fear of sexual inadequacy. Also, certain medications can pose a problem in intimacy. For our male patients who are taking sulfasalazine, it can affect the ability of the sperm's motility, and also, methotrexate is contraindicated in inflammatory bowel disease patients looking to get pregnant.

Ms. Rubin:

Thanks, Ashley, for that information.

Ms. Perkovich:

Michele, are there any surgical issues regarding intimacy and IBD?

Ms. Rubin:

Oh, yes, there are several. First of all, the proctectomy with removal of the rectum, it involves a proctocolectomy, and in a J-pouch procedure, in each case we're removing the rectal segment. In women, you can see dyspareunia, which is usually pain on intercourse due to adhesions. In men, you will see weak erections because the nerves that run along the rectum get manipulated and it takes a while for those sensations to return. With a J-pouch, there is fair stool incontinence due to the sphincter muscle strength that gets stressed during removal of the rectum. And with an ileostomy, these patients wearing the appliance, they feel dirty; sometimes they feel that the appliance gets in the way or that they're going to have a leak or a blowout during intimacy. With perianal procedures, a lot of times there are fistulas that are draining purulent material. They may have a seton in place, which is a rubber band to keep the fistula tract open, and they feel dirty. Sometimes, there are smells during intimacy. They feel the pain and they feel the pulling of the setons. So, it's a very definite factor in intimacy with surgical procedures often.

Ms. Perkovich:

Thank you for explaining that.

Ms. Rubin:

And here, Ashley, actually is a recent study that just came out in the *IBD Journal* in June of 2018, and it was a physician at Brigham and Women's Hospital as well as an institution in Denmark, and they were focusing in on Crohn's disease often involves the use of biologics and potentially surgeries which could significantly affect surgical function, and they used a validated IBD female sexual dysfunction

survey which included 15 questions on the specific management of UC and Crohn's, and the findings that they found were that up to 60% of women with IBD reported sexual dysfunction. That's pretty good. And 40% of the women were afraid of experiencing pain with sex. They felt unattractive due to their IBD. Two-thirds of the women said that IBD had led to distress in their relationships. In 28%, IBD activity had prevented them from having sex, and women felt guilty or fearful about sex. IBD was associated with depression, and worse disease activity definitely was a factor. Pelvic pain, diarrhea, bleeding, could affect a woman's libido as well as her comfort with having sex, feeling very fatigued, particularly due to disease and activity that is not well controlled. So, this was kind of a very enlightening study, and we do not see many studies on intimacy.

Ms. Perkovich:

No, we don't.

Ms. Rubin:

And here was, actually, the result of that study, what their findings showed, and they felt there was definitely a psychological component. Women with IBD feel very fatigued, particularly if their disease is not well-controlled, and that, in itself, can affect sexual function. So, their conclusions stated that providers need to be more aware and discuss sexual dysfunction with their IBD patients. And there really is not very much information out there, Ashley. They could hardly find any on the sexual dysfunction in male in IBD patients, so I think we have a lot of work to do in that area.

Ms. Perkovich:

We do, we definitely do.

Ms. Rubin:

And here was another recent survey that was done on ulcerative colitis patients. one of the huge gaps that was noticed is that intimacy is important to many patients in ulcerative colitis management, but they are not always being addressed during physician visits. Forty-two percent of patients they saw were having issues and felt that there was a great impact on their sex life and personal relationships. They felt it was very important to them. And 42% of those patients said that they did not even feel comfortable bringing this up with their providers during a visit. But then the other interesting side of this is that only 4% of gastroenterologists felt that it was one of the top 3 topics of priorities during routine appointments with nearly 2/3 of gastroenterologists, or 64%, reporting that they never even discussed this with their patients.

Ms. Perkovich:

Wow, what a great study. So, Michele, what can we do?

Ms. Rubin:

I always say during visits, "Let's just ask." Providers need to be more aware of sexual dysfunction in their IBD patients and more open to discussing it. So, start by asking patients about dating or intimate relations at each visit. Let them know that it is common to have concerns and issues with intimacy. Talking about it may help patients feel more at ease and develop confidence to ask questions. And remember to involve the significant other in conversations as well. when I'm asking these questions, I'm looking over at their significant other, and they're there nodding going, "Yep, that's right, absolutely true," and so couples therapy is also an option in this, as well.

Ashley:

Good point.

Ms. Rubin:

And so these problems definitely involve a multidisciplinary team. You have the dealing with the medical issues with the gastroenterologist. You have the surgeon where some of these surgical procedures are impacting their desire and intimacy as well as psychology, because it definitely is a psychological issue as well with many of these patients.

Ms. Perkovich:

I would agree. Definitely, you need to ask because these patients are not forthcoming with this information. And also, I think it's important that you are examining them at their routine visit. So, if it's somebody who is having multiple bowel movements a day, ask them if they're having any perianal irritation. If it's somebody with a history of perianal Crohn's disease, make sure you're looking at the area. If there's nothing you can see physically on the outside when you're examining your patient, consider ordering an MRI of the pelvis or even a CT scan to further assess and get to the bottom of the problem. And then, of course, you should remember to use

medications when appropriate. So, if your patient does have an abscess or a perianal fistula, oftentimes our patients require courses of antibiotics or even chronic antibiotics to keep that area clean to prevent those abscesses form recurring. And in your patients that have skin tags and hemorrhoids that can become inflamed, remember to use topical therapy when appropriate, and don't forget to get a surgical consultation when needed.

Ms. Rubin:

So, Ashley, what can we do here to help with this gap in communication?

Ms. Perkovich:

You know, we can offer simple recommendations that might help decrease the bowel movements or leakage of stool before intimacy, such as taking Imodium; going to the bathroom; emptying the J-Pouch or ostomy appliance prior to intimacy; with a stoma, try using a smaller appliance, if applicable; wearing a camisole to cover it so that your patient feels more secure; and don't forget to refer patients that are having sexual dysfunction to either the gynecologist, pelvic floor therapist, psychiatrist or behavior therapist—important for their spouse or partner to also be there; recommend patient support groups, because they are not alone—other patients are dealing with these exact same issues; and try to make them feel comfortable in bringing these issues up because you're not going to help them at all unless you're talking about it. And the most important thing we can do as their providers is to keep the disease under control. The Crohn's and Colitis Foundation has many resources regarding intimacy issues and inflammatory bowel disease on their website. Please visit www.crohnscolitisfoundation.org for resources for providers as well as resources to share with patients, including shared decision-making.

Ms. Rubin:

So, thank you, Ashley, for joining me today. I think this was an excellent discussion on intimacy and IBD.

Ms. Perkovich:

Thanks, Michele.