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

Addressing the Prevalence of Psychosocial Issues in IBD

Ms. Rubin:

Today we're going to talk on psychosocial issues in inflammatory bowel disease. Welcome, Ashley.

Ms. Perkovich:

Thanks for having me, Michele.

Ms. Rubin:

Oh, it's a pleasure. So, Ashley, perhaps you can start us off today and talk about some of the issues that are involved in psychosocial issues in IBD.

Ms. Perkovich:

Because IBD is a chronic disease defined by periods of disease remission, followed by periods of disease flares, we need to remember to empathize with our patients coping with these matters. When one is given the diagnosis of IBD, there's a lot of uncertainty, unpredictability, and even the chronicity of the disease itself can cause a wide range of psychosocial and interpersonal concerns for patients, and these include loss of control of bowel function, impaired body image, social isolation or dependency, the fear of not reaching their full potential and feelings of self-unworthiness. So, when patients have anxiety and depression, it can also affect their adherence to their medication regimen, which then would put them in a disease flare. Oftentimes, patients have anxiety related to administering medications as there is a stigma associated with injecting medications and receiving medications via IV infusion. Some patients even have a fear of needles. And certain medications have side effects, such as prednisone, which can cause mood swings and anxiety. And that's the medicine side, Michele, but are there surgical issues?

Ms. Rubin:

Oh, yes, Ashley, there are quite a few, actually. With surgery, there are physical changes, there are a lot of concerns about what is going to change due to the surgery, and there are many fears. in ulcerative colitis, particularly the proctocolectomy with the ileostomy, there is a fear of losing the rectum–and strangely as it sounds, it's their rectum and they're like, "Oh my gosh, what happens when that is removed? Am I really going to be a whole person?"—and then the permanent ileostomy, of course, where they feel dirty, the appliance seems to get in the way, "Is somebody going to see it?", the fear of having a blowout or a leak, and just hearing passage of gas.

With a J-pouch, they're concerned about how many steps. There are 2 or 3 steps to completion. How many bowel movements are they going to have? Is it going to be more or is it going to be like just what they were feeling with the disease, and are there going to be leaks of stool?—fertility concerns with the dyspareunia and the weak erections.

And then in Crohn's disease, you're having recurrent surgeries with bowel resections. Do I have enough bowel left? Can I eat regular foods again? Will it affect my bowel movements? Am I going to have a lot more now because intestine was removed? And then with perineal disease, there are recurrent fistulas, abscesses and seton placement, even to the point where they have a distorted anal and perineal area. There is a lot of scarring with the disease–setons, which are the rubber-bands that are hanging to keep the fistula tracts open so they don't develop an abscess, and the draining pus, again feeling dirty. They feel they smell, and it's painful to sit.

So, Ashley, can you tell us a little bit about the psychological issues that they deal with?

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Ms. Perkovich:

Yes. Depression and anxiety are very prevalent amongst our patients. With depression, sometimes they feel as if their life is over. They are ashamed of their disease. Oftentimes, our patients become withdrawn or have decreased socialization. They feel like they can't go out of the house because they don't know if they'll have access to a bathroom or have a possible accident of stool. Oftentimes, too, they feel dirty because of their disease, and they really lose control over their body and sometimes their life. And even beyond depression, I feel like anxiety is a really big issue because there is a lot of unknown regarding IBD. Will their medication work? Will they require surgery? They are anxious to come to visits, they are anxious to get their test results back, and they're anxious if there family and friends will accept them.

Ms. Rubin:

Yes, and in addition, Ashley, is the posttraumatic stress disorder. And I see a lot in the younger patients in particular, I would say, patients with the chronic disease, just the chronicity of it and the flaring and the going into remission, multiple surgeries particularly for the Crohn's patients, the recurrent hospitalizations and complications of the disease, the bad experiences that they have, and they develop flashbacks, which the patient sometimes cannot overcome, and they sort of relive the whole disease experience every time they come to the clinic visits, so it's very devastating. And sometimes this gets in the way of being able to treat them when they do come to the visit. And the other thing is narcotic addiction, Ashley. The chronic pain that these patients sometimes deal with, coming to the ER for frequent visits, and a lot of times they get pain medication because that's what they're coming in with.

Ms. Perkovich:

It's an easy fix.

Ms. Rubin:

Yes, it's an easy fix. And then there is the multiple-treating-physician ordering that goes on,

Ms. Rubin:

So, Ashley, can you talk a little bit about prevalence of these issues?

Ms. Perkovich:

Yes. So, prevalence of anxiety and depression has been estimated to be as high as 29 to 35%, even during remission. And during a relapse, prevalence of anxiety is as high as 80%, and the prevalence of depression during a relapse is as high as 60%, so it's important to know that anxiety is a little bit more prevalent than depression, but they're both there more often than they're not there.

Ms. Rubin:

Well, Ashley, here is a survey that was done this last year on ulcerative colitis patients, emotional health is important to many patients in ulcerative colitis management, but they aren't always being addressed during physician visits. So, what they found here is about 1/3 of patients, which is 34%, wish that their gastroenterologist better understood how much this impacted their mental health. However, more than 1/3 don't feel comfortable talking about their emotional concerns with their gastroenterologist. Complicating this, 94% of physicians don't think mental health issues are one of the top 3 topics to prioritize during routine appointments, and nearly half of gastroenterologists, 49%, never discuss the impact of ulcerative colitis on patients' mental emotional health.

Ms. Perkovich:

That's such a shame.

Ms. Rubin:

Yes, it is such a shame.

Ms. Perkovich:

So, Michele, what can we do? What can we do to address these issues with our patients?

Ms. Rubin:

Again, Ashley, I say just ask. Let the communication begin and ask them, "What does the typical day in your life look like? Are you spending time socializing with your friends? What would you like to talk about that concerns you most during this visit?" And then ask them, "Do you sometimes feel depressed or anxious?" So, discussing these issues will help patients understand it is okay to talk about

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their feelings and begin to take control of their lives and their feelings. Acknowledge you understand what they are going through and that you want to help. Let them know that it is common for IBD patients to experience depression, anxiety or posttraumatic stress disorder with a chronic disease, and let them know, “You are not alone.

Ms. Perkovich:

I completely agree. I think that psychologic intervention that’s aimed at stress reduction may potentially even reduce disease activity. Things like stress management, relaxation training and IBD-focused counseling have been useful for both psychologic problems and the clinical symptoms of inflammatory bowel disease. It is really important with the psychosocial issues to engage the patient in the treatment process, and this all starts with shared decision-making, so really helping them to get involved and take control of their disease. Some of your patients may require medications to treat their depression and anxiety. Tricyclic antidepressants have been reported to alleviate psychological distress, but they also have somatic effects in helping to reduce pain, irritability, and the urgency of defecation. And remember to educate your patients. Discuss the risks and benefits of treatments, medical treatments, surgical treatments, and address their concerns and their fears with both of those things.

Ms. Rubin:

So, I agree totally with that, Ashley, and again, just ask. Open the conversation and then refer them. Refer them to a behavioral therapist or a psychiatrist, and if you don’t have them in your own centers, then give them a list of nearby therapists in their area that they can call. Address narcotic issue if it is noted. Use depression and anxiety questionnaire tools. That’s another huge benefit to give them to a patient and then see the results, and it will exemplify if they do have any depression or anxiety. And the other real important piece is refer them to patient support groups, where they identify with each other and they can talk about the issues, And utilizing ostomy nurses if they have an ileostomy, they are of utmost importance in teaching them how to manage the ostomy

The bottom line is, get the disease under control and in remission. That is what we, as providers, need to do, and help to give the patient more control over their disease and their life.

Ms. Perkovich:

Please visit the Crohn’s and Colitis Foundation website at www.crohnscolitisfoundation.org. There are many resources for providers and patients alike, including support groups, peer-to-peer support and a broader online community.

Ms. Rubin:

So, Ashley, thank you so much for joining me today. I think this has been a wonderful discussion on the psychosocial issues in IBD, and I think we have given them some really helpful tips to use in their practice to help our patients with IBD. So, thank you, Ashley.

Ms. Perkovich:

Thanks, Michele.

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