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Tackling the Taboo: How to Talk About Intimacy with IBD Patients

Dr. Nandi:
Let's talk about sex. Sex and inflammatory bowel disease, to be more precise. While Western media is replete with distorted images of body image and warped standards of beauty, it ironically and sadly still remains taboo to talk about sex in the clinic. If heterosexual relationships were still challenging for most clinicians today, there's even less training and insights on how to approach these vital matters in our LGBT intersex patients. On this episode of the podcast, we're going to take a brief dive into sexuality and intimacy in inflammatory bowel disease patients.

Joining me today is Dr. Jordan Axelrad and assistant professor of medicine at NYU Langone Health in the Center for Inflammatory Bowel Disease. Among Jordan's research interests are studies of malignant and infectious risk in IBD patient populations. And notably, Jordan is an IBD patient himself and physician advocate who regularly lectures both patients and clinician symposiums. Jordan, it is an absolute delight to host you on our program today. Welcome to *GI Insights*.

Dr. Axelrad:
Thanks, Neil. This is obviously a very important topic. And I look forward to sharing my perspective.

Dr. Nandi:
Dr. Axelrad, I just want to ask you just from the get go, why is there such a lack of research do you think in inflammatory bowel disease and sexual health, and how is this changing? And why should GI doctors even care?

Dr. Axelrad:
So as you alluded to in the intro, this is obviously a very sort of taboo topic. And it's taken many decades for us to approach sort of more of a comfort level with the topic overall. And you and I both know that patients have very detailed questions about sexual functioning, intimacy, relationships, but oftentimes even today, patients are very hesitant about initiating that conversation. And so between hesitancy on the patient end, hesitancy on the physician/clinician end, and just the sort of taboo feeling overall about the topic have deeply impacted knowledge and research in this area. And even to this day, there's extremely limited research examining sexual functioning and intimacy and sexuality in inflammatory bowel disease.

Dr. Nandi:
When is the right time that a GI clinician should address this? Is there a right time? Or when do you recommend a clinician try to broach this subject with a patient?

Dr. Axelrad:
Well, I think it's critically important that clinicians recognize that sexual relationships and sexuality for many of us is a critically important part of our lives. And even when we're not in a relationship, sexuality remains a part of who patients are. And so, as a clinician, if we are uncomfortable talking about sex and sexuality, obviously our patients will be too. And I would argue that there should be every opportunity and any opportunity to broach the subject. And I think it's especially important to pick up on cues from patients, if they're interested in talking about sex, sexual function, sexuality, and so forth.

It's important for us obviously, not just to make our patients feel comfortable, establish good rapport, and be able to interact, but also to understand the right ways in which to interact with a patient. So it's very important that we use neutral and inclusive terms. If that's not entirely clear, you can ask the patients for things like their pronouns or their sexuality. That's completely within the realm of okay. And patients would much rather be asked than have there be an assumption. And that is another important part, which is that we need to avoid assumptions and try not to react. And I think for us, and we practice in major metropolitan areas with a lot of cultural diversity,

sexual, and gender diversity. And in other places, patients may not be so lucky, or clinicians may not have that experience.

So I think just understanding as clinicians that we need to use neutral and inclusive terms, avoid assumptions, rephrase questions. And if you're not familiar with the term or something that's kind of confusing, ask the patient. Ask the patient what's going on because that will really help to break down barriers. If you make that assumption that a patient maybe is straight instead of queer, if you make an assumption about someone's gender identity without asking, that really creates a huge barrier and probably would prevent a conversation on the topic or being able to achieve a much better doctor-patient relationship.

And I would just add one other point that there has to be also a stress to patients that patients also need to be open and honest from the beginning of their relationships with their healthcare professionals. Because if that relationship isn't open and honest, then that'll set sort of unrealistic expectations moving forward. And yes, there's like this big hierarchy in the room, and then patients may feel nervous about being open, but that's really important. And if that relationship is not open and sort of easy, then perhaps patients should seek out more culturally competent physicians, caregivers.

Dr. Nandi:
Yeah, absolutely.

Jordan, does your approach change about asking about sexual health? Are there certain things you ask about in certain populations that are not heterosexual? Or lesbian, gay, or intersex populations? Are there unique questions? Or do you have a checklist?

Dr. Axelrad:
So I don't exactly have a checklist because I think that this is very individual, right? And so the advice for sexual health and sexual function are similar regardless of one's sexual orientation, or gender identity, realistically. So feelings about intimacy, feelings about body image, that has no gender or sexual orientation. With that said, of course, there are certain populations that engage in certain sexual practices that are directly linked to the GI tract. So for example, patients who engage in anal receptive intercourse now, this doesn't have to be limited to gay men, all patients can engage in receptive anal intercourse. And so it's extremely important to actually have the information about what these practices and how they may interact with one's disease course and how to talk about that specifically to a patient. So I don't specifically have a checklist, but certainly there are questions that I ask patients and that may include targeting those who are undergoing surgery; A, to talk about body image, but B, to also talking about things like sexual functioning, you know, receptive anal intercourse, and what that looks like in order for there to be good recovery and good functioning in the post-operative period, for example.

Dr. Nandi:
Very good. I like how you said there's really no checklist a lot of these things are common to whatever your orientation may be. And anoreceptive intercourse is practiced by all people, regardless of gender orientation. We get that question commonly.

Let's begin with that.

So with anoreceptive intercourse, we have patients, heterosexual, homosexual, or whatever, who participate. During a flare, we obviously try to discourage that because that may create trauma during that time. However, for patients who may not be in flare or for patients who are not in flare, but may have a pouch?

Dr. Axelrad:
Sure, so this topic is poorly studied. There are virtually no studies to indicate whether sex, for example, can trigger flares. Or there's few studies examining the appropriate guidance for how long patients need to wait after surgery or after they have a pouch before engaging in anal sex, for example. So given the lack of data, this has to be a point of discussion between patients and providers. And what's really critically important about this is that depending on, in the surgical population for example, depending on what's done, that can have an impact on function. So for example, if patients have maybe had surgical staples, that's important to know because that can actually cause trauma.

Depending on where an anastomosis is, right, a connection between two parts of bowel, that can also determine what the safety level is for engaging in some sexual practices. So it's very important, especially in the surgical patient to have that open and honest conversation when relevant.

The second point about flares is that since we have very little knowledge about whether sexual activities can trigger flares, there's little guidance here. Of course, I recommend to all patients who are in flare to avoid receptive anal course, for example, because if there is bleeding and diarrhea, trauma to the area, it can definitely increase the risks of complications and bleeding and whatnot. So that's something that all patients should avoid. And generally, most patients who are not doing well are not interested in engaging in something like receptive anal intercourse.

However, for patients who are doing well in remission, they're certainly no extra precautions other than the baseline precautions for all patients engaging in sex that needs to be done. And I think that's really important to explain to patients.

Dr. Nandi:
That's very helpful. Jordan, thank you very much.

For those just tuning in, you're listening to *GI Insights* on ReachMD, and I've been speaking with Dr. Jordan Axelrad of NYU Langone IBD Center, specifically on sexuality and intimacy in inflammatory bowel disease.

Now, Jordan, we've been speaking about different populations, we just talked about different gender populations. We've talked about anoreceptive intercourse. And another population that often gets not well studied I'll go for I'd say is ignored, sadly, are ostomates. And we have many ostomates in our IBD community, and body image dissatisfaction is highly prevalent and their confidence in their sexuality and their physique. What kinds of advice can you give clinicians in broaching the subject? And what can clinicians help their patients with? If this is an issue for their ostomate patient in terms of engaging in sexual activity, what can a clinician advise?

Dr. Axelrad:
So body image, especially in patients with an ostomy is a huge topic. And I think that we're actually lucky to live in the sort of social media era because that's allowed patients to access a network of ostomates worldwide. And so years ago, when I was talking about ostomy with patients, I never referred them to social media. But now because there is such an empowering presence of ostomates on social media, that's allowed for a much broader connection and discussion about body image in particular and sexual functioning across the world.

And so my approach to a patient and talking about an ostomy is that body image is probably the first thing that I bring up and talking about an ostomy and how that impacts relationships and sexual functioning, and all other aspects of mental health and physical health. So that's an extremely unique challenge that IBD, especially ostomy surgery, poses as it relates to intimacy and sexual functioning. And not just having an ostomy but surgery in and of itself, scars, scar tissue, pain, all these things contribute.

And so the first thing that I usually recommend is finding your support group, right? So it could be a patient's partner, it could be through social media, a group of patients who have undergone ostomy, finding ways to not just come to terms with living a stoma, but how to function one's best life with a stoma is obviously incredibly important. And then understanding that closeness of a relationship to each patient so that they can have an open and honest conversation with their partners about sex and intimacy and anxiety is also a critically important part of the recovery and living with IBD.

As far as unique guidance, again, very little research into sexual functioning and sexual activity in the ostomy patient. And I think a lot of that has to do with the disease activity and what surgery was done. And again, that's about that open, honest conversation between the patient and the clinician to understand the risks and benefits and what's safest and how a patient can be honest about discussing that.

Dr. Nandi:
Absolutely. Are there any particular organizations that you would recommend that patients go seek for ostomy education in regards to sexual health and/or just sexual health resources in general?

Dr. Axelrad:
Yeah so recently, the Crohn's and Colitis Foundation has put out some fact sheets and information on sex, intimacy, and IBD. They're important. I edited them and I helped write them, so I would definitely point clinicians towards the sex and intimacy fact sheets through the Crohn's and Colitis Foundation. Also, the Crohn's and Colitis UK has also very robust information sheets as well, but it's much more detailed actually than the Crohn's and Colitis Foundation, one about sexual relationships and IBD. They talk about gender and sexual minorities, sexual functioning. So that's also very important.

And I would also point patients to social media, right. There's such a broad network now on Twitter and Instagram and Facebook about ostomates and post-op patients, and queer patients with IBD. That's all out there. And establishing those connections, even in the absence of the presence of a clinician can really help patients directly. And so I always encourage patients when they're undergoing surgery or have issues about body image to find that group online to look at patients who are thriving in their own lives to understand how to best function postoperatively or with this diagnosis and so forth.

And then the very last thing I'll mention is that this is an area of ongoing research, right? There's very little known, but we're attempting to learn more. So I would also point clinicians to look forward to publications out of consortia looking at sexual functioning and practices in patients with IBD. And hopefully, we'll have more information soon.

Dr. Nandi:
Dr. Axelrad, thank you so much for joining us on the program. Do you have any last closing remarks before we conclude the program?

Dr. Axelrad:
I think just in closing, I would just advise clinicians and patients to be well informed as possible, right, because that just allows for a much better connection between the doctor-patient relationship and that's most important

Dr. Nandi:
Absolutely. Knowledge is power. Thank you so much, Jordan, for being with us today. For ReachMD. I'm Dr. Neil Nandi. To access this episode and others from *GI Insights* please visit ReachMD.com/GIInsights, where you can Be Part of the Knowledge. Thanks for listening