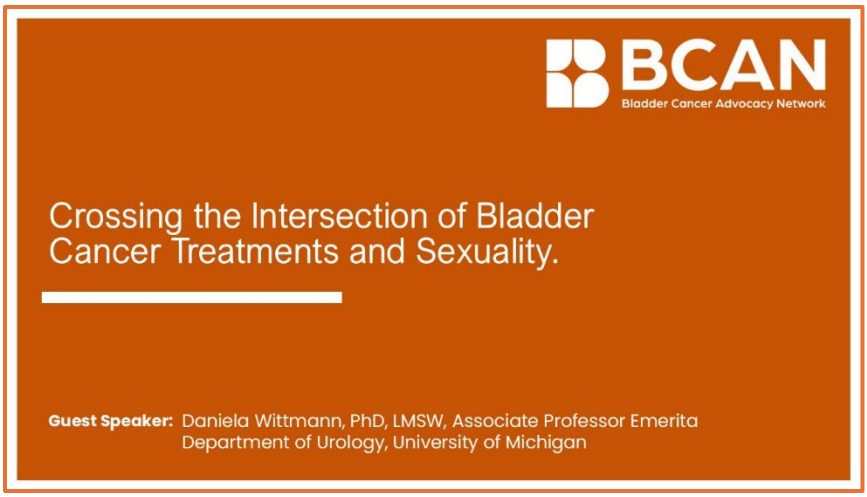

PART 4 of 4

Patricia Rios:

Dr. Wittmann, thank you so much for such a comprehensive presentation.

We'll go into the Q&A session, but before we do that, I have two quick announcements. One is to remind our listeners that this webinar is being recorded and that it will be available on the BCAN website two to four weeks from today. Also, the button at the bottom of your screen with a symbol Q&A or a question mark, that's the button you use to submit your questions. And I see we already have a few and I'm going to read those out loud for you. Dr. Wittmann.

This one says, "Hi. I had a radical cystectomy, ileal conduit at University of Michigan in August of 2022. Consequently, I only have maybe an inch of vagina left. My husband, though supportive, finds my having an urostomy bag less than appealing to him, thus we have zero intimacy. Is there a way to have intercourse, let alone regain intimacy after all this time?"

Dr. Daniela Wittmann:

Could you repeat what of the vagina is left after the surgery?

Patricia Rios:

This person says maybe an inch of vagina left.

Dr. Daniela Wittmann:

So if there is an inch of a vagina left, it's unlikely that there's an ability to have intercourse. However, there are other ways of having sex and this is the situation that access to a sex therapist, and a discussion with both the patient and her husband would be really important because this is the one about expectations and refiguring out how the sex is going to happen, but all means, it's not too late. As long as there's enough emotional connection with the couple and both people want to find a way forward, it's absolutely something worth pursuing.

The University of Michigan has a center for sexual health. I think there is a fairly long waiting list there, but that person can look for sex therapists in the state of Michigan. There are lots of them here.

Patricia Rios:

Excellent, thank you for answering that. We'll go into the next question which says why do they need to take women's vagina with iliac conduit but not with a neobladder?"

Dr. Daniela Wittmann:

I'm not sure that that's true. I think that even with a neobladder, a part or the whole vagina may be taken. The neobladder is made out of the intestine. And so depending on the extent of the cancer, that's what determines how much of the vagina gets taken, not the kind of diversion that a person will end up with.

Patricia Rios:

Great, thank you. I also want to take a minute to mention, and we'll put the link in the chat, during our patient summit last fall, we had a urologist, Dr. Trinity Bivalacqua, who also presented on the management and the medical management of sexual dysfunction. And he goes into a lot of detail about that. So we'll put the link. So if you weren't in attendance, you can watch that recording. So thank you Dr. Wittmann.

This other question comes from one of our patients that says, "Can a non-invasive muscle bladder cancer patient through diet and exercise improve testosterone and or nitric oxide levels to enhance sexual drive/performance?"

Dr. Daniela Wittmann:

Well, you are really bringing up a subject which is the topic of emerging research, and that is that diet and exercise can improve sexual function. There are some studies that have shown that it can improve erectile function, that it can improve testosterone levels. And it would definitely be recommended that anybody who wants to improve their sexual function should engage in healthy diet and exercise

because think about it, if you are feeling good in your body because you are exercising, it gets you more in touch with your body. So even without the testosterone, you will feel more interested in using your body in a variety of ways. But there is beginning research that shows that a plant-based diet particularly and exercise improve sexual function.

Patricia Rios:

And in that question, he mentioned nitric oxide levels. Could-

Dr. Daniela Wittmann:

Yeah, nitric oxide is a mechanism that gets affected in a prostatectomy. There's a disruption of that mechanism. I'm not a physician, so I don't really want to address it directly, so I don't know whether it addresses nitric oxide, but that's a good question. Maybe to discuss with... This is a good question, for example, for a sexual medicine physician. If you have one, if a urologist who has in his or her practice a sexual medicine physician or is a generalist him or herself, they would be able to answer that question. And ask them to look up the research because they may not know it, but they can look it up.

Patricia Rios:

That's an excellent suggestion. Thank you. So during the presentation, you talked about some of the concerns on non-muscle invasive and you mentioned the term vaginal stenosis. Can you explain what that is?

Dr. Daniela Wittmann:

Yes. Vaginal stenosis is something that can happen sometimes just based on removing ovaries, vaginal atrophy can happen. That can actually happen to women also after menopause. Then also if there's been radiation to the pelvic area that can cause vaginal stenosis. What that means? That means a narrowing of the vaginal canal so that when then the penis tries to penetrate is very painful. There's also lesser elasticity of the vaginal walls, which makes it harder. And so that's why the vaginal moisturizers, the lubricants, sometimes stretching with vaginal dilators and sometimes hormonal supplementation, estrogen supplementation can be helpful.

Patricia Rios:

Now, this is a female and she explains, "Before surgery, I asked to preserve as much as my vagina as possible. Intercourse is painful. How do I know if there's enough vagina left?"

Dr. Daniela Wittmann:

Excellent, wonderful question. Somebody needs to look in and tell you. So that could be a gynecologist. It could be physical therapist. Probably gynecologists would be the best person to start with to see. You could also just ask your urologist, "How much of my vagina did you take?" if they haven't told you that.

Patricia Rios:

Great question. All right. You mentioned abstaining during BCG. For a male receiving BCG, does this apply only to vaginal intercourse? Would it be safe if a condom was used?

Dr. Daniela Wittmann:

Well, I think that the physicians generally recommend that regardless, because it's something that's trying to kill the cancer that therefore it's got a certain amount of toxicity, you would probably abstain. So they would probably say don't even... I mean, it's not a long abstention. Anyway, I think that maybe two weeks or something like that. I don't know specifically, but if they did tell you you can use a condom, then you shouldn't.

Patricia Rios:

Okay. All right. Here we have a... Let's see. "I just learned that the muscles in my..." Oh, goodness, it disappeared. Okay. "I just learned that the muscles in my penis have been the generating since my radical cystectomy and neobladder surgery two and a half months ago. Are you aware of men who have recovered from a similar situation to have a normal sex life?"

Dr. Daniela Wittmann:

There are men who have recovered erectile function after prostate removal. This is usually based on age, so the younger, the better, and also on erectile function before any kind of treatment for bladder cancer or for prostate cancer, before the removal of the prostate. So yes, there are men who recover the erectile function. It's not a large number of men. It's probably about 20%, but it exists. And anybody who obviously recovers erectile function is extremely pleased. There are many men who recover to the point that they can begin to use those PD-5 inhibitors, the pills rather than the more dramatic aids such as the pump or the injection. And one of the main things that people talk about is the loss of the spontaneity when you have to use medicine or the pump. And obviously the ability to have spontaneous erections is highly desirable. And if that's happening to anyone in this audience, I'm so happy for

you. But it can take up to two even years or longer. So if you're six months out and it hasn't happened and you had a really good sexual erectile function before surgery, don't give up.

Patricia Rios:

You're right. This listener says that both bladder and prostate were removed and lost that loving feeling, will it come back? And also looks like he had chemo and radiation early on. It says, "I can stimulate my wife, but I cannot be stimulated. Any suggestions for others that are experiencing similar?"

Dr. Daniela Wittmann:

I'm not 100% sure what is meant by that loving feeling. That could be desire. That could be pleasure. That could be orgasm. I'm not sure what is meant. So low desire is not unusual in that circumstance. And it can be based on the psychological experience of having lost so much that it doesn't feel good and right. And sometimes men, when they don't have erectile function that is reminiscent to what they had before the surgery feel very sad. And so that interferes with desire. Erectile dysfunction is pretty typical after this kind of treatment. So that would not be surprising. Really, any man who's had surgery, even those men who have had radiation should be able to have the ability to have an orgasm, continue to stimulate and don't give up. Now, I didn't remember whether this person had hormonal therapy as well of any kind.

Patricia Rios:

It wasn't mentioned.

Dr. Daniela Wittmann:

No. Okay. That certainly takes desire away, erectile function away, and sometimes orgasm as well. So the ability to have an orgasm should not be gone or should be able to return over time with continuous stimulation, but erectile function and low desire are pretty common.

Patricia Rios:

All right, we have a question about, and this was submitted before today's webinar. The question says, "Our new normal, including intimacy, means overcoming our emotional fatigue. What are some ways to manage our emotional fatigue?"

Dr. Daniela Wittmann:

Well, the best way probably to do it is to set aside time. So very often, sex therapists talk with their patients about setting time aside as a romantic date and find a way to relax with music, with scents, being in a relaxing environment, maybe take a shower together, maybe take a bath together, something that will be soothing. Some people can't get there right away and may need to do that.. May do that relaxing activity that's setting aside of aside time on their own before they can get to the partner relationship. If you find that this is really not working for you, just find a sex therapist and have a more detailed discussion about your situation and what would help.

Patricia Rios:

That's helpful, and that leads me into this other question. I think during the presentation, you talked about feeling comfortable talking about this topic. A patient mentioned that since they had cancer, the husband doesn't want to have sex and the patient doesn't know how to address this subject. So what tips do you have for that individual?

Dr. Daniela Wittmann:

Well, if they are not talking, then I would recommend they go see somebody. When we did our research, actually that was in prostate cancer some years ago, we found that a big majority of people really don't talk about sex. They can have great sex for 40 years and never have to talk because they have figured out a way of touching each other, of making sounds that has worked for them and it's been fine. And now they have sexual problems and they don't know how to talk. People are uncomfortable saying words. People are very afraid of hurting each other's feelings, and they have the worst fears about what the other person is thinking and feeling. And they just something where sex therapists can really help because they really start helping with that conversation to find out what are people feeling? What is it that makes them uncomfortable? What is it that they are fearful about? What preconceptions they have about what sex is? That is a big one. That is a big one for people who might think that intercourse is the only way to have sex. And it's so not true.

I found in my practice that when people are willing to talk about it, be flexible, learn other things to do, one of the things I have to do is talk. And so the emotional connection becomes stronger. And when people have more of an emotional connection right along with searching for the sexual connection and sexual pleasure in a new way, it can make them closer. Number one, because they've overcome a problem together and they may have to both grieve to start with, but also building

something in spite of all the assault on the body and on the relationship, building something together that is intimate and that is pleasurable can be very powerful. And people can feel like... And this is something we found in our research as well, that those people who grieved who were reasonably flexible and re-engaged in sex, albeit in a different way, ended up feeling like they built something very special and felt very, very connected.

Obviously it's not going to work for everybody, but there's a really good opportunity that that would happen. And sometimes it's necessary to get help and it's really good to get help. At the University of Michigan, we have a sex therapist embedded in prostate cancer care, and I think that it should be done in bladder cancer care too. We don't have that. So it's important to take initiative, find a sex therapist, go there together and start the conversation.

Patricia Rios:

And when finding that sex therapist, what are some of the tips that you can give us in terms of questions to ask to ensure it's a good, fits the needs that one patient has?

Dr. Daniela Wittmann:

Well, I think that any sex therapist will ask, what brings you here? What are the issues that you're facing? And we'll ask questions about, what it used to be like? What is it like now? What are some of the barriers that you're feeling? What solutions have you tried? So I think at the end of that, that therapist should give some ideas about how to proceed. And then the question is, can you help us? It's really the therapist who will do the asking. The main thing that the patient and the partner need to do if they want help is to go find it and feel entitled to it because everybody's entitled to have a sexual relationship that works for them. Everybody is entitled.

Now, it has happened in some relationships that maybe one partner wants to continue, the other one doesn't. Then there's a different kind of grief that's involved. That's very hard and it's very painful, but it's definitely not the outcome that is most often there. It's just that people are not used to working on sexual problems. It's a very sensitive topic. People just don't want to hurt each other's feelings. And when you start protecting each other, then you can't get anything solved. And a sex therapist is the kind of person who will not have that barrier, right? It's their job to discuss with both of you what ails you know, what it is that you're having a hard time with. And being able to listen to each other, hear each other out, find a way of accommodating and finding a way of realizing that you're in it together can be very helpful.

Patricia Rios:

Well, Dr. Wittmann, thank you so much for creating a safe space for us to have this conversation. I hope everyone who has joined us today leaves empowered. And I think the word that you used that stuck with me, that we're entitled to this service. And so I want to remind all of you that in the chat, there's links to the various resources Dr. Wittmann mentioned. So if you'd like to look for a sex therapist near you, please check out those websites.

And before we conclude, Dr. Wittmann, I like to ask our speakers to leave us with the keywords or message that you want us to take away from the presentation.

Dr. Daniela Wittmann:

We are all sexual beings. Our sexual self is an integral part of who we are. And if we are not well in every other area, we go and seek help because we think, of course, we should seek help. We should do that for our sexual lives as well. That goes along with the statement that we are entitled to have a good sexual life, and we are entitled to have sexual experiences in spite of our chronic conditions and disabilities. We are sexual beings, and that is core to our existence.

Patricia Rios:

Thank you so much. And with that, I want to thank Dr. Wittmann for joining us today and for sharing her expertise with us and to you, our listeners, for joining us. We look forward to seeing you at another BCAN Patient Insight webinar series. Have a wonderful day and we will see you next time.