

Conversations: Let's Talk About Bladder Cancer

Understanding Sexuality After Bladder Cancer



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Diane Z. Quale:

Welcome to conversations about bladder cancer. I'm Diane Zipursky Quale, the co-founder of BCAN, the Bladder Cancer Advocacy Network. Most people aren't comfortable talking with strangers, even their own doctors, about their sex life, but opening this line of communication becomes critically important for bladder cancer patients and their partners. Joining me to talk about how bladder cancer treatment affects sexuality, both physically and psychologically, and how to talk with your medical team about these concerns are two experts in the field, Dr. Trinity Bivalacqua, urologic oncologist and sexual medicine specialist from Johns Hopkins Hospital in Baltimore, and Dr. Daniela Wittmann, a psychotherapist and certified sex therapist at the University of Michigan in Ann Harbor.

Thank you both for joining me today. We really appreciate your time and you're sharing your expertise. Now, we know when someone learns they have bladder cancer, especially muscle-invasive bladder cancer that might require bladder removal surgery and urinary reconstruction. Their first concern, justifiably, and their doctor's primary concern is saving their life. Too often, the conversation about how to live your life fully following the treatment never occurs. That's the conversation I want us to focus on here, and help patients feel more comfortable with having this conversation with their own doctors.

Daniela, can you start us off with providing a general explanation of what sexual dysfunction means. First, for me and then for women.

Dr. Daniela Wittmann: Okay. Let me start by saying what sexual function is. What people think of as sexual function is what we think of as the human sexual response. It starts with the desire, interest in sex, goes to arousal, excitement. For men, this means erections. For women, that means lubrication, vaginal lubrication. For both of

them, intense experience of pleasure. The pleasure with stimulation intensifies until a person reaches orgasm. After orgasm, there's a kind of a resting period called resolution which is the time that people, both men and women, can feel kind of satisfaction with the experience.

Sexual dysfunction is a problem with enjoying the pleasure of sexual activity and participating in it comfortably. For both men and women, this may be low desire, low interest in sex. For men, in the arousal arena, it means problems with erections. For women, problems with lubrication. Sometimes, both men and women can have trouble with orgasms. Any of those phases of the human sexual response can be a part of a dysfunction. When people cannot participate, both men and women, in the response with comfort and pleasure, that's a dysfunction.

Diane Z. Quale: Okay. Trinity, can you tell us what the likelihood is that patients will experience any kind of these sexual issues following bladder removal surgery.

Dr. Trinity Bivalacqua: Yeah. I think, we're now going to talk mostly about patients that undergo ... They have muscle-invasive bladder cancer and are undergoing bladder removal. Those patients, either men or women, had very high likelihood of having some form of sexual dysfunction. As we heard in men, we hear a lot about erectile dysfunction or problems with obtaining or sustaining erection because a cystectomy removes both the bladder and the prostate in men. The nerves that are responsible for erection can be damaged, can be removed, at the time of surgery. If a surgeon removes those nerves, then a man will never be able to obtain an erection.

There are things that we can do as surgeons to help preserve erectile function. Despite us being wonderful surgeons and being able to help our patients, that you will still have a time period after surgery, after nerve-sparing surgery, where you have erectile dysfunction. The thing that we try to do to teach our patients is that that time of recovery could take four to five years before they, ultimately, regain erections.

Diane Z. Quale: Years.

Dr. Trinity Bivalacqua: Years, not months. The earliest some men is going to obtain an erection is probably 12 to 18 months and those erections are not going to be really functional erections so they will need help. They will need aids.

Diane Z. Quale: That's really ... That's a very long time, I would say, for most patients just hearing 12 months is long time but when you're saying four to five years, that could seem like a lifetime.

Dr. Trinity Bivalacqua: It sure is especially for young, healthy couples that are having to deal with this over a two, three, four year period.

Diane Z. Quale: Can you talk about ... The erectile function with the men, how about with women who've undergone the surgery?

Dr. Trinity Bivalacqua: As you've heard from Daniela, one of the problems with sexual dysfunction in women is women losing the ability to have lubrication. Now, this is something that's a result of either damage to nerves or the vascular supply to the vagina. As surgeons, once again, as we're removing the bladder, oftentimes, the whole entire anterior surface of the vagina or the uterus and ovaries are removed so this can do two things. It can actually shorten the vagina so makes it difficult for vaginal penetration and it can also damage nerves and blood vessels that are responsible for the lubrication aspect of sexual response.

As surgeons, we can do things, once again, for women and that is that we can preserve the anterior portion of the vagina to help with vaginal [inaudible 00:06:30] to allow for penetration. We can also do nerve-sparing. There are nerves that supply the clitoris that are responsible for orgasm and also helping with lubrication. Now, there are some women just like in some men where nerve-sparing or preserving the anterior portion of the vagina just is impossible due to locally advanced cancer. These are decisions-

Diane Z. Quale: You mean where the tumor was or ...

Dr. Trinity Bivalacqua: Where the tumor is or was and where we have to be more aggressive with our surgery. Our goal is to identify who we can do nerve-sparing on in men, who we can preserve the anterior portion of the vagina in women and do nerve-sparing in women, to help them regain their quality of life as it relates to sexual function post-surgery.

Diane Z. Quale: For women, post-surgery, what's the timetable for them to regain more of the function.

Dr. Trinity Bivalacqua: I told you in utmost confidence that it will take many years for men to regain it.

Diane Z. Quale: Exactly.

Dr. Trinity Bivalacqua: The problem is, in women, we really don't know. What I can tell you from my-

Diane Z. Quale: Why don't we know?

Dr. Trinity Bivalacqua: Because there's been very little research done in this avenue. This is a perfect place for us to understand the causes and, really, the timing of recovery for women. Now, women are a lot more complex than men as Daniela sort of alluded to in her sexual response.

Diane Z. Quale: In so many ways.

Dr. Trinity Bivalacqua: In so many ways. For women, it's more than just the act of having sexual

relations with their partner. It's also the intimacy and also, sometimes, just the life-changes and sort of body-change that occurs after surgery. For some women, it's actually more important to sort of have the intimacy there and that's actually a conversation that physicians have to have with women as to what are their expectations following surgery.

Diane Z. Quale: Daniela, can we switch a bit now and talk about the emotional impact the sexual issues have on patients and their partners?

Dr. Daniela Wittmann: What I want to say, initially, is that when people know what to expect, the transition and the emotional impact is a little bit easier. In general, people, both men and women, experience a sense of loss because now their normal function has been changed dramatically and they don't really know the timetable fully for the recovery. They may become anxious. They may worry about what they're going to be like as a lover and whether they're going to be able to meet the sexual needs of their partner. The impact on the partner is worry about the person with the bladder cancer and uncertainty about how to proceed, not to want to put pressure and so on.

As long as people can talk, they can go through the process of grieving the losses and finding a new way of being erotic together well. It won't be easy but it will be all right, but for many people, for a long time, sex is very non-verbal and so talking about it becomes difficult so that can become a problem for the couple. However, there's a great that people can learn and do to go forward to regain some form of sexual intimacy after bladder cancer treatment.

Diane Z. Quale: A lot of that has to do with communicating as a couple.

Dr. Daniela Wittmann: Yes, absolutely.

Diane Z. Quale: My understanding what my partner needs and just understanding what I might need too.

Dr. Daniela Wittmann: Yes, exactly.

Diane Z. Quale: Trinity, can we talk a little bit about ... given the length of time that it might take for patients to get back to normal. Are there treatments or things that can be done to help alleviate these issues during this long healing process?

Dr. Trinity Bivalacqua: One of the most important things that we do and we discuss with you, the patient, is that there's expectations that need to be set forth in the beginning. For men and their partner, we have to educate them as to this time period of recovery and let them know that it is going to take a significant amount of time to get back to what we call their baseline. They may never get back to baseline. During that process of healing or the nerves recovering, then we have a lot of erectile aids that we can use. Some of those are pills like you've seen many commercials on television.

Diane Z. Quale: Like Cialis.

Dr. Trinity Bivalacqua: Like Cialis. Like Viagra. These should be used immediately after surgery. What I do in my clinical practice is, is that if I have a patient, doesn't matter if they're 40 or if they're 70 and they want to be sexually active, we start them immediately on medications by mouth as needed, right? So, Viagra or Cialis.

Diane Z. Quale: This is immediately after surgery.

Dr. Trinity Bivalacqua: Immediately after surgery. Now, there will be, occasionally, some patients that will respond very, very nicely to that, fresh post-op. Those are usually young patients. Those are patients in their 40s or 50s. Okay? If you do not respond to the medication, then we proceed directly to other erectile aids. Those are things like called injection therapy where we teach patients how to inject into the penis medications that will give them a functional erection. Other things are ... something called a vacuum erection device. These are ways to be able to help the patient, a patient, to begin a functional erection.

Now, as you heard, sometimes, that's not important for a couple because it's also important to educate a man that you can have an orgasm without having an erection, right? This is something that is also oftentimes lost in discussion with patients. There are lots of things that we can do. Sure.

Diane Z. Quale: What can we do for women immediately after surgery.

Dr. Trinity Bivalacqua: Once again, for women, it's a process of healing. As I spoke about when a woman undergoes cystectomy, we have to, occasionally, remove a part of the vagina so it has to heal. That process of healing usually takes somewhere between three to six months. For them, it could be painful so lubricants can be utilized to help and then additional stimulation to obtain orgasm is, oftentimes, necessary. Because those nerves, even though we may spare those nerves, they still take time to regenerate and to recover.

I often will tell women that, listen, this is a process of healing and this will take time. Okay? There is no magic pill for women. There is actually an FDA-approved medication for women with female sexual dysfunction. However, it's never been tested in the setting after cystectomy so we really don't know its utility.

Dr. Daniela Wittmann: Okay. Can I mention a couple of other things for women?

Diane Z. Quale: Yes.

Dr. Trinity Bivalacqua: Sure.

Dr. Daniela Wittmann: One would be pelvic floor rehabilitation to release scars, to make the vaginal

and the perineal area more comfortable.

Diane Z. Quale: Those are exercises [crosstalk 00:13:46].

Dr. Daniela Wittmann: Those will be exercises. They could be some massage, trigger pointing. Physical therapists are very good at that. Sometimes, it can be the use of dilators for women who have shortened vaginas to stretch them a little bit more again so that they can be more receptive to the penis. While there are methods for creating erections and for dilating vaginas to enable intercourse, there are all kinds of ways of being sexually intimate. Trinity already alluded to, you know, you don't have to have an erection to have an orgasm. You can use manual stimulation or you can use oral sex. We often recommend vibrators because they are very good for blood flow. Blood flow is very good for sexual sensitivity. In some ways, couples have to re-learn what feels erotic to them and that requires a bit of experimentation.

Dr. Trinity Bivalacqua: You heard a little bit about pelvic floor exercise. Just like women and men that undergo orthotopic neobladders see their physical therapists for, sometimes, six months. That's actually a lot of the same exercises. People, men and women with neobladders are actually doing that already.

Diane Z. Quale: But they don't know that it could have the impact on their sexuality.

Dr. Trinity Bivalacqua: They don't know. Right. They don't realized it. Correct.

Diane Z. Quale: This is a great conversation with the two of you as specialists and talking in great detail. How can I even start this conversation with my own doctor?

Dr. Daniela Wittmann: First of all, you have to have some idea that this is an important topic too. If it is important to you, then what you can do is think for yourself what questions you have and write them down. Talk to your partner. Get ready for that conversation. Let your doctor know that this is something that you want to discuss and so start asking by asking a question about what kind of effect is this treatment, this surgery going to have on my sexual function. Can you explain that to me? Then, is there anything that I can do about it to maintain sexual activity and sexual pleasure? What are the resources that I can access? Are you the person who's going to be able to help me with that or are there other sexual health specialists that can help me? Those are the kinds of questions that can be asked of the doctor and people usually feel anxious about it. Physicians don't always feel comfortable either.

Diane Z. Quale: I was going to say ... Trinity, what if I ask these questions and my doctor says, "Oh, it's just very important that you have the surgery and we'll deal with all that at the other end. I'm just trying to save your life."

Dr. Trinity Bivalacqua: The next step is simply asking your physician, it doesn't matter if it's your medical oncologist, your radiation oncologist, your urologic oncologist. Is there

someone in your practice that specializes in sexual health and sexual medicine? I can have an honest conversation with them to understand what impact this treatment is going to have on me and every single clinical practice has someone that specializes in sexual medicine. It's simply just learning about the fact that this is going to happen and I want to learn what I can do as a patient to improve my recovery of sexual function post-surgery or post any treatment. I think, every single practice both academia as well as in clinical private practice has specialists that can assist.

Dr. Daniela Wittmann: I want to add to Trinity. He's mentioning the sexual medicine specialists. They are also sex therapists so, often, practice in the community who can particularly help with the relationship aspects of sexual recovery and they actually work very well with sexual medicine physicians as a team to help a couple or an individual regain their sexual capacity. There is an organization in the United States called the American Association of Sexuality Educators, Counselors and Therapists. They have their website and you can go on the website and find the sex therapists in your state. Then there's also the Society for Sex Therapy and Research and on their website you can also find people who are near you.

Diane Z. Quale: Wonderful. Wonderful. Any others, Trinity?

Dr. Trinity Bivalacqua: Then, as a urologist, there's always the American Urological Association and Care Foundation that has a number of resources for patients that have sexual dysfunction, particularly, erectile dysfunction as well as female sexual dysfunction. Another great organization is the Sexual Medicine Society of North America. They have a wonderful website that also can link you to a specialist in your area, someone that may be in Omaha, it could be in California, it could be in Upstate New York. They actually allow you to be able to look for someone that specializes in sexual health that you can see. There's two great resources.

Diane Z. Quale: I think, another point we need to make is this is an issue to be discussed before surgery, but then it's an issue to be addressed and treated for the many months or years following surgery and that there are resources and people out there that can help us resume a healthy and full of life, both physically and psychologically.

Dr. Daniela Wittmann: Absolutely. You know, as patients say to us, so to you as a patient, I would say this should be talked about before surgery, after surgery and it should be repeated often because you never know when people are ready to start working on their sexual recovery. It may be soon but it may be six months later. It should be discussed on a periodic basis.

Dr. Trinity Bivalacqua: We, as clinicians, can assume that a patient is interested in sex or not interested so we should address it often, always. It doesn't matter if it's three months later or five years later. The first thing that we have to do is exactly what we're doing here today which is educate. We need to educate patients.

We also have to educate our bladder cancer specialists that this is important. Once we do that, I think, we will be able to have an opportunity to really help all patients that are suffering with this disease.

Dr. Daniela Wittmann: Yes, yes. Because these people are surviving and living, they need to restore the quality of their lives and sexuality is a very huge part of it.

Diane Z. Quale: Exactly. Exactly. Thank you very much and one of the takeaways I want for our audience is if your doctor is not asking you these questions, don't let that stop you and you should be asking these questions of your medical team. Trinity and Daniela, thank you so much. It's been a pleasure. For more information, please be sure to check out the Bladder Cancer Advocacy Network's website at bcan.org. Please, be sure to check the links to these helpful sexual health organizations.

