



Crossing the Intersection of Bladder Cancer Treatments and Sexuality.

Guest Speaker: Daniela Wittmann, PhD, LMSW, Associate Professor Emerita
Department of Urology, University of Michigan

PART 1 of 4

Patricia Rios:

We are kicking off our 2025 webinar series with an amazing presentation titled Intimacy Redefined: Navigating Sexuality During Bladder Cancer Treatment. There is no argument that bladder cancer treatment such as chemotherapy, surgery and radiation can profoundly impact physical and emotional aspects of sexuality, posing challenges for patients and their partners. Today, Dr. Daniela Wittmann will lead us into an engaging discussion on the intersection of cancer care and sexual health. Specifically, Dr. Wittmann will discuss common concerns, effective communication strategies and resources to help you or a loved one navigate these changes.

Let me tell you a little bit about our amazing speaker. Dr. Wittmann is a clinical associate professor emerita at the University of Michigan's Department of Urology. She's a psychotherapist, educator and researcher. She was a lead faculty in developing the Brandon Prostate Cancer Survivorship Program and is currently the associate director of the Weiser Center for Prostate Cancer at the University of Michigan. She's certified as a sex therapist and sex therapy supervisor by the American Association of Sexuality Educators, Counselors and Therapists. Dr. Wittmann has published research reviews, opinion articles and chapters on sexual issues in cancer and urologic diseases.

Dr. Wittmann, it is an honor to have you here with us today. I will now turn over the screen to you and ask our participants to please use the Q&A button to post your questions throughout the presentation. We'll address those at the conclusion of Dr. Wittmann's presentation.

Dr. Daniela Wittmann:

Well, thank you very much for the kind introduction, and I want to say that I'm so happy to be here to meet with all of you. For some of you who were at the Philadelphia Patient Summit, I was unable to come because I was sick. So this is my opportunity to meet with you and with anybody else who decided to join this webinar. And thank you BCAN for putting a spotlight on sexuality in bladder cancer.

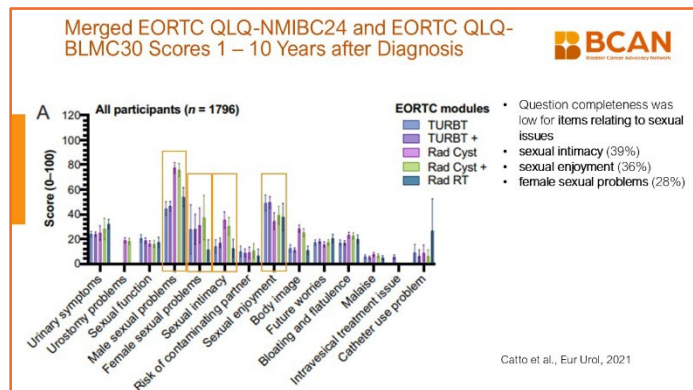


I don't have any disclosures for this presentation and I'm going to start with a few statistics.

So the American Cancer Society publishes statistics on the number of cancer survivors in the United States. They do it about every five years or so. They publish on incidents and mortality every year, but this is a more rare event. So the data we have is from 2019. And as of 2019, there were over 620,000 male bladder cancer patients living in the United States, or bladder cancer survivors, I should say, and over 200,000 female bladder cancer survivors. So that's a pretty big number and I would expect that it's probably a large number today.

Dr. Daniela Wittmann:

Every now and then too, the people who treat and study bladder cancer, they look at outcomes, and most of them they look at oncological outcomes, but sometimes they also look at the side effects of treatment. And this is a study that was conducted in Europe and they looked at the kinds of functioning, the kinds of psychological consequences of bladder cancer treatment to find out



what were people coping with in survivorship, what were people bothered by. And as you can see, the descriptions of the colors of the TURBT and TURBT plus is related to noninvasive bladder cancer. And the cystectomy colors are related to patients where their bladder are removed. And then there is one color bar that is devoted to people who underwent radiation.

And what you will see when I click was that the major concerns that men reported were sexual problems. The same was for women. Sexual intimacy stood out as well, as did sexual enjoyment. And I should add that when the female patients were filling out these questionnaires, there was a smaller number willing to answer those questions. So that makes the results a little bit less solid than for the male patients, but I think it's true nevertheless. It's

sexual problems are something that patients identify as something that bothers them in survivorship.

Dr. Daniela Wittmann:

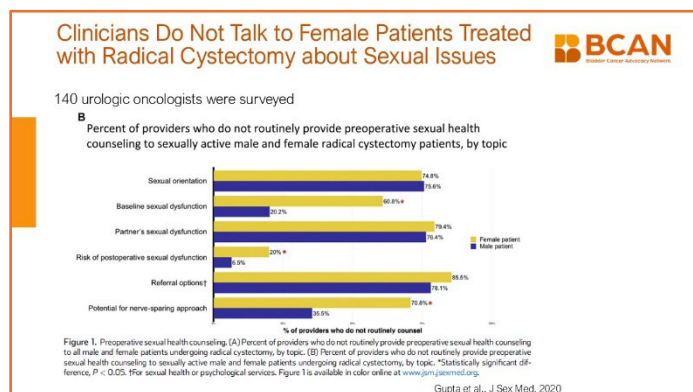
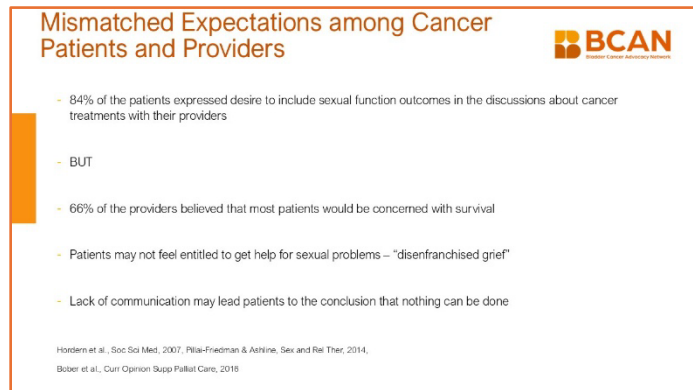
Now, the unfortunate thing is that there's a mismatch between patients and their healthcare providers. Over 80%, 84% of patients in the literature say that they want to include their sexual function outcomes as a part of the discussion of their cancer care, but more than 60% of providers think that patients are more concerned with survival than with their sexual function

as if one couldn't be concerned about both. And I will tell you from my own clinical experience that when I first became a sex therapist in cancer care, the oncology clinicians would say to me, "The patients are not going to talk to you about their sexual lives. They are only concerned about the cancer." Of course, it wasn't true whatsoever.

Now, one of the things that prevents the conversation too is that some patients feel that they are not entitled to ask about what to do about the sexual concerns. Sometimes people have said to me, "My doctor has already tried to cure my cancer. How am I going to ask him or her for another thing?" So they don't feel entitled to ask for that. And so this becomes a loss that is then grieved and it's a disenfranchised grief in the sense that it's not seen by these patients and maybe sometimes by some providers as legitimate, but of course it's totally legitimate and I just want to emphasize it here. So the lack of communication leads to the fact that men and women with bladder cancer don't find out about how to understand the sexual problems. They don't find out about rehabilitation, and they are left hanging in survivorship. And while the rest of their life may be going quite well, this area is not addressed.

Dr. Daniela Wittmann:

Now, there was a study done at Johns Hopkins where they ask oncology providers around the country to tell them how much they talk to their bladder cancer patients about sexual health. And these were patients with radical cystectomy, so with the muscle-invasive bladder cancer. So these providers that were asked, and on this graph you see what the clinicians did not address. And in blue, you have men. In yellow, you have women. So you will



see that they did not discuss sexual orientation, baseline sexual function, the partner, sexual problems, referral options, and potential for nerve-sparing.

And I want you to pay attention too to the disparity between the genders. You can see here that a significant number of female patients were not counseled about baseline sexual function, i.e. that was not assessed, risk of post-operative sexual dysfunction, so they were not prepared that they would have it, and then potential for nerve-sparing approach, which today is something that should really be discussed with every patient, whether there is a potential for nerve sparing because it can protect sexual function. So many topics of non-sexual health were not discussed with any patients, but especially with female patients. And this is an important disparity that we have to keep on educating our providers that they should not be discriminating.

Dr. Daniela Wittmann:

Now, what these clinicians said was that they thought the patients were older, and so maybe they didn't care, they didn't have time to discuss that may be somewhat legitimate. They were uncertain about the patient's baseline sexual function. Well, if uncertain, you should measure it. And they were concerned that the patient would be uncomfortable. There's also

all this research that says that patients think that the physicians are not going to be comfortable. So there's this mutual protection going on and then the discussion is not had. But for only 5% of these urologists so that this was outside the scope of their practice, in other words, 95% of these clinicians saw sexual health counseling as within the scope of practice. So they say that, but they're not doing it. So that is a problem in the field, and I imagine that some of you, at least in the audience have encountered this.

Dr. Daniela Wittmann:

So there are consequences when we don't talk about these things in cancer care.

I saw a woman in my practice. She was 50 years old. She had a new nail brother, and during that time, she lost her uterus and ovaries. So after she was treated and recovered, she came to me with her husband. She told me that her neobladder was functioning beautifully,

her urinary functions better than before the surgery, but she said, "Nobody ever told me that I

Clinicians' Perceptions of Barriers to Sexual Health Discussions

Table 3. Provider-reported barriers to sexual health counseling of female patients undergoing radical cystectomy and their partners

Barrier	n (%)
Older patient	140 (50.7)
Inadequate time	47 (17.1)
Uncertain about patient's baseline sexual function	37 (13.7)
Concerned patient would feel uncomfortable	37 (26.4)
Lack of knowledge about female sexual function	28 (20.0)
Uncomfortable counseling patient/partner	15 (10.7)
Outside the scope of urologic oncology practice	7 (5.0)

Gupta et al., J Sex Med, 2020

Not Talking about Sexual Concerns Has Consequences

- 50 yo woman with a neobladder who had lost her uterus and ovaries
- 58 yo woman with ileal conduit revision surgeries

"I searched for resources to help with my sexual problems. I found a Menopause Institute in my area. They did a 2-hour evaluation and sent me to physical therapy. It was only then that I learned that a vagina may have various sizes after a cystectomy, and that no matter how much dilating I would do, my husband and I would never be able to have intercourse"

"Nobody ever told me that I would go into menopause. It hit me hard. My interest in sex was always low. This made it much worse for my husband and me"

would go into menopause. It hit me hard. My interest in sex was always low and this made it much worse for my husband and for me." So she had not been informed that at 50, if she hadn't gone through menopause, she would be thrown into menopause. And when it happened, she was astounded, shocked and very upset.

This is a patient advocate who told Liz a story about her own experience. She had had an ileal conduit at 58 and then had to have several vision surgeries. And she said, "I searched for resources to help me with my sexual problems. I found a menopause institute in my area. They did a two-hour evaluation and sent me to physical therapy. It was only then that I learned that a vagina may have various sizes after a cystectomy and that no matter how much dilating I would do, my husband and I would never be able to have intercourse." I mean, this was astounding information for her, which was never explained to her before or after her surgery. So you can see that there are significant consequences for people when that kind of conversation and counseling doesn't take place.

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