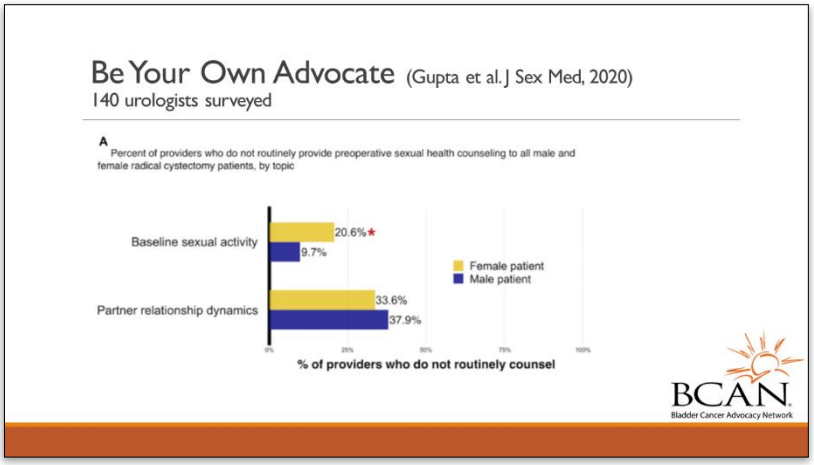
Being Your Own Advocate and Finding A Sex Therapist

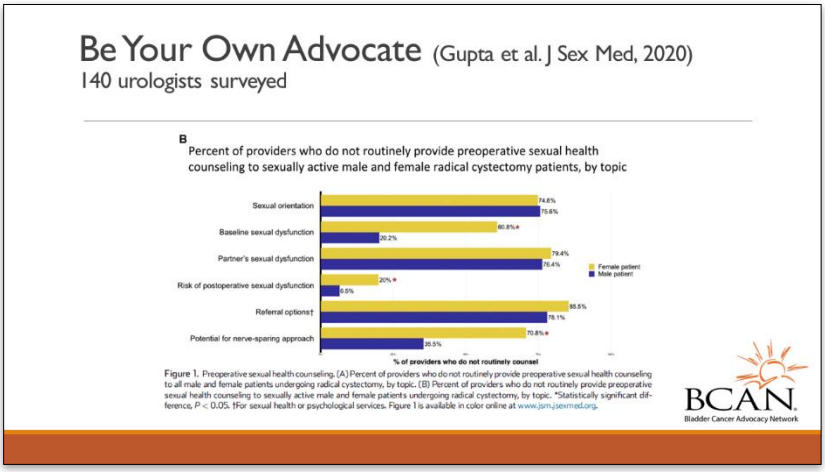
Dr. Wittmann: One of the things that I want to emphasize before we end is that, to be quite honest, in every cancer and so therefore in bladder cancer too, the patient has to be her own advocate, because oftentimes people don't discuss sexual issues, physicians with their patients. So this study was done at Johns Hopkins with urologists who do bladder cancer care. They have surveyed about routinely providing any kind of sexual health conversations with their patients. And this is what they found. They found that, as many as almost 21% of women never have that discussion about baseline sexuality at the time off running the surgery.



I want you to notice the statistically significant and difference between women and men. This is true not to just in bladder cancer. This is also true as I know in heart disease.

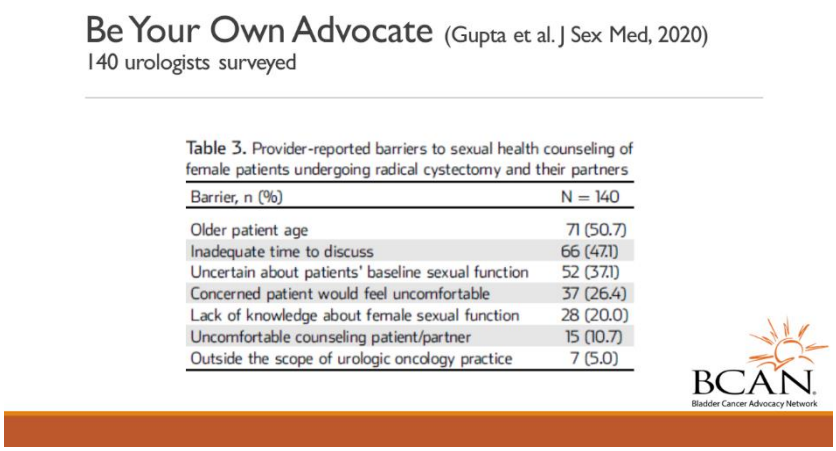
That there's the tendency to approach men about their sexuality much more so than women. And again, I think that there are cultural components that may also be that until recently, most bladder cancer surgeons were men and maybe didn't feel comfortable to talk to women, but it's a problem. And quite a good proportion don't discuss anything thinking about the relationship. And here are the topics that are not covered.

Sexual orientation, look at it. Only 25% off providers discuss sexual orientation for both men and women besides sexual dysfunction assessment. Look at that. As many as 61% don't discuss this with women and 20% not with men. The partner's sexual dysfunction, almost 80% don't discuss. The risk for post operative sexual dysfunction, so that is really important for funding because as definitely we were saying earlier, these days that it can be an effort to do some nerve sparing and maybe organ sparing to protect sexual function. I mean, obviously consequential comes first, but this is something that is considered.



Well, if the conversation never takes place, the patient never knows that maybe there was a chance to do some nerve-sparing, or if there isn't a chance to do nerve-sparing that they know why that was not possible. Mostly providers don't offer referrals, and mostly particularly with the women, they don't discuss nerve-sparing. So you can see that still today, you're less likely to get it from the provider then you should. And so that's why I'm saying, it's really important for patients to be advocates for themselves. I was at a research conference at the American Urological Association last year in the spring, about gaps in care for women with bladder cancer, and that totally one of the topics there.

Sexuality is not discussed and it's a gap in care in general. So here are the barriers that the providers said they had. One was that they saw that if the patient is older they don't discuss it. So they must think that people who are older don't have sex, which is not true we know. Inadequate time to discuss, that they think is legitimate. Uncertain about patient's baseline sexual function. Well, we have to measure it. It's uncertain that the patient will be uncomfortable. I think that the uncomfortable counseling patient or partner is probably the sure part, because most people will be comfortable if their provider is comfortable discussing it.



Dr. Wittmann: Lack of knowledge of female sexual function I think is really also an important part. So there's a fair bit of education about how to talk to patients and also about female sexual function that urologists needs to have early in their training, so that they can have that conversation. So that was my presentation today. Thank you for your attention. And if there are any questions or comments, I would love to entertain them.

BCAN | Stephanie Chisolm:

You just mentioned a couple of slides ago that providers say that they don't make referrals, especially for women more so than for men. So how do you recommend a patient bring this up with their provider, and get a referral to either a pelvic floor, physical therapist or a sexuality counselor, therapists that can help them work through some of the details with or without their partner?

Dr. Wittmann:

So, I would say that the best thing to do would be number one, just sit down, write down some questions, how has this bladder cancer and the treatment for you affected my sexuality? This is my experience. I now don't lubricate. I don't now don't feel any desire. I feel pain when I have intercourse, any of those things. How has my cancer treatment affected that number one? Number two, who can be helpful with this? Do you know any sex therapists in the area? Does your hospital have pelvis floor rehabilitation specialists in physical therapy who can help me?

And when those questions are sit down, then sometimes it helps to let the urologist know that you're going to be asking those questions, so that they can be prepared. If you just need an extra appointment, it's completely legitimate and reasonable to ask that. I think more and more urologists realize that they need to know who the sex therapists are in the area, and that they need to have relationships with physical therapists who have this specialty, because really survivorship care is all about multiple disciplines.

It's not only surveillance for the cancer; it's really quality of life. And so patients can definitely push the agenda. So setting down the questions and then letting the provider know that you're going to be asking.

BCAN | Stephanie Chisolm:

And finding a sex therapist. Can you talk a little bit about how people can go and visit AASECT website, maybe if you spell that out for them and how they could look for somebody?

Dr. Wittmann:

Absolutely. So right there is this website of the American Association of Sexuality educators, Counselors and Therapists, AASECT.org. And maybe I should've really put it on a slide. And if you go to that website, there is a map of the United States. You click on your state and you will get a list of all sex therapists in your area in alphabetical in your town, or you will get a list of certified sex therapists in the area. And those are all people that are certified to do that they've passed numerous, rigorous exams. They know what they're talking about. If you just did a Google search for sex therapists, you could get all kinds of crazy things and you could be susceptible to all sorts of weird emails. So please go to AASECT.org if you are looking for a certified sex therapist.

BCAN | Stephanie Chisolm:

And couples with pain during sexual intercourse, so you didn't really address pain specifically, what patients would be able to do in the sense of helping with reducing pain from sexual intercourse. I know you talked about lubrication and you talked about a number of other things, but what about the pain that comes from the actual act of intercourse? This particular person's husband wants to have sex and

she says she's just not interested. Where does she start? If it's going to be painful, nobody wants to engage in that right off the top.

Dr. Wittmann:

That's definitely a barrier. So I think for first would be to go to a gynecologist and get an evaluation off the vagina. Because depending on the treatments the vagina may be shorter, the vagina may be affected by radiation. So the gynecologist will look in and see what the vaginal walls look like, how possibly just to stretch the vagina. And that a gynecologist will then do a number of things. Maybe the gynecologist … If the vagina for example is in fairly good shape. But the vaginal walls are fragile and dry, the gynecologist may recommend Vagifem, that medication that I mentioned. However, if there is scar tissue or shortened vagina, the gynecologist may that the woman goes and sees a physical therapist to evaluate, what and how much can it be done to stretch the vagina to make it more comfortable from the scar tissue, to be able to have more comfortable vaginal intercourse. It may take time. Some of these exercises, some of these interventions can take time because the skin may take time to adjust and to adapt and to relax a little bit. I think there will probably be some cases where it's not possible. But I think it's always worth trying to get that assessment and then trying to get that assessment with the physical therapist, to see how these interventions could help.

BCAN | Stephanie Chisolm:

Great. Thank you. That's really useful information. So you mentioned that again, sometimes it's the provider either making assumptions because a woman and or a man is older, they're not interested in sex. Maybe that's part of what keeps them from talking about it. But how can patient advocates and patients themselves really work to encourage surgeons and the urologists that are treating them with all the other types of intravesical treatments, how can they encourage these professionals to really begin to think about this topic? I know that it's addressed the medical education programs, and yet people they'll carry in their perceptions of older patients maybe not be having sex so much. How do you bring that up to them?

Dr. Wittmann:

So first of all, I would like to say that actually it's not very well addressed in medical education. People may get the class in medical school but it's not a part of clinical learning. If somebody is following and doctor in a clinic, medical student or a resident, they're not hearing about it, so they don't think it's something that they should be discussing themselves. I think a person has to be very courageous, and decide that they're going to be the ones who are going to educate the physician that even though they're 65, 70 years old, that sex is still important to them. It's important to their partner and they need help.

I think one of the things that patients run across is, the physicians don't really have resources that they figured out, so they don't know who to refer to and how to provide those resources. So just by saying to a doctor that sexual health is really important to you, and that you have this website and that you know about pelvis floor rehabilitation, the physician can send somebody to pelvic floor rehabilitation. They may not know much about it, but once the patient is gone there and if they get help, that physician will have learned that that patient got help with sexual health from a physical therapist or a sex therapist. So it's really kind of by doing. It's very challenging, because in most situations I found that patients wished that provider would address it, because they're not comfortable, and they don't even know whether it's legitimate to bring it up, but it is totally legitimate. And those patients, who are willing to do that with their providers, will really move that provider forward in their maturity as a clinician.

BCAN | Stephanie Chisolm:

That's a really excellent point. A lot of people have real anxiety about bringing up sexual topics, and especially admitting that they're even interested in some ways in sexuality. So think about if this is important to you and you bring it up, and then you report back your successes and how things might have improved or how you've adapted. You can educate all of these other providers as well that become more aware that this is in fact an issue. So, patients don't know what they don't know. They don't always know how to ask. How can we include this information in terms of people who are newly diagnosed?

BCAN | Stephanie Chisolm:

When you're told you have cancer, your biggest concern is, "I want that cancer out of my body." You don't think about what happens after the fact. If doctors aren't talking to patients about this preoperatively, how do you suggest here? Obviously BCAN is doing our bit to get the word out and let people know that this is an important factor that goes on with bladder cancer treatment. If patients don't know that this is an impact that they might experience, how do we work to inform them in general, because people don't talk much about sexuality as you mentioned early in your talk.

Dr. Wittmann:

Well, I think the only way that we do it is that we do research and present it at scientific meetings, to show physicians that this is really important to patients. We did a study on sexual concerns of breast cancer and prostate cancer patients at the University of Michigan, and found that patients had on average four sexual concerns. And they generally we're about, concerns about how their body would function sexually, about how to satisfy a partner and about being able to experience pleasure. So we know that patients are concerned. I think the only way to influence physicians is to have it be more of a part of the education, and then also presenting the research. On a day-to-day basis, I think BCAN is doing a great job in publicizing the topic. And I think any physicians who go on the website, also see it. And the other thing is, things like … I hate to put the burden on the patients. Well, I guess you're saying what if the patient doesn't even know this is the consequence? I'm not quite sure how to make that happen, because as you say, people are worried about the cancer. Though I've found that if you tell people that your sexual function is going to be affected, they may not want to discuss it right there and then, but they'll remember it later on that you were willing to discuss it with them and they're glad that you're willing. I think it's education, disseminating information over and over again about this.