

Scott Redding: Welcome to the 3Ps of Cancer podcast, where we'll discuss prevention, preparedness, and progress in cancer treatments and research, brought to you by the University of Michigan Rogel Cancer Center. I'm Scott Redding. We're here with Daniela Wittmann, associate professor of urology, who is one of the leading members of the Prostate Cancer Survivorship Program. She is an AASECT certified sex therapist and a sex therapy supervisor who has over 30 years of psychotherapy experience. Dr. Wittmann's research includes the use of mixed methods to study the effect of cancer on sexual health, and the development, testing, and dissemination of interventions that promote sexual recovery after cancer treatment. Welcome Daniela.

Dr. Daniela W.: Hello.

Scott Redding: Can you tell us about the importance of a prostate cancer survivorship program?

Dr. Daniela W.: Yes. As you well know, how many people would know, prostate cancer, especially if it's found early, is a highly treatable disease. Men are treated and then they spend a lot of years in what we call prostate cancer survivorship, which means that they live not only their regular lives, but they also live with the side effects of the prostate cancer treatment. Our Brandon Prostate Cancer Survivorship is devoted to those side effects. What we do is that we help men and their partners manage expectations for what the side effects of treatment are going to be like. We tell them about the rehabilitation that's available, and then after treatment we are there as a team to support them, to help them with rehabilitation, both the physiologic, the emotional, and the couple related aspects.

Scott Redding: What would you say out of these expectations and some of the concerns that prostate cancer patients have, what would be that number one issue that men and their partners fear about prostate cancer?

Dr. Daniela W.: After surgical treatment for prostate cancer, men have two major side effects. One is urinary incontinence and the other one is erectile dysfunction. I would say they worry about them both. It kind of depends on the man, which one is going to be more bothersome. One of the things that we can reassure a man is that over 90% of them will recover bladder control, so they will not be incontinent in the longterm. It's a kind of a more short term bothersome side effect. The sexual recovery, the recovery of erectile function is much longer and less predictable for the individual man, so we focused quite a bit on that in survivorship. But, we certainly help with both. I would say, again, it depends on the individual man and both of them can be bothersome.

Scott Redding: Addressing those concerns in particular, is this something that is done kind of presurgical, postsurgical? How does that all work?

Dr. Daniela W.: All right, so we have kind of a basic package that we offer to every patient, and I want to mention something very important. Partners are always invited to all the appointments in survivorship because we understand that these side effects affect the partner as much as they do the patient. We start with a preoperative seminar. Before the surgery, we invite men and their partners to essentially a lecture and discussion about outcomes associated with prostate cancer surgery. It's presented by a multidisciplinary team. We have a surgeon, we have nurses, we have physical therapy, and myself, I'm a sex therapist.

We tell them, "These are the outcomes you can expect in terms of the cancer. These are the outcomes in urinary incontinence and erectile dysfunction. This is how you're going to likely respond emotionally to all of this." Then, "Here are some of the ways in which we help you recover from the side effects." It's kind of our way also introducing patients and their partners to the team that awaits them after the surgery to support them.

Scott Redding: You talk about this multidisciplinary team that they get to meet that is part of their care at the seminars offered. Could you go a little more detail about exactly kind of what that might look like and what that might entail?

Dr. Daniela W.: Okay, sure. Let me just start out by saying that the minute a patient signs up for surgery, into their calendar of events will be placed this preoperative seminar, and we do the seminar once a month for men who are about to undergo surgery the following month. We get about 80% attendance. The people who don't come largely don't come because they live too far away. They come to a large auditorium. We are ready with a PowerPoint presentation where we tell them about the various side effects and outcomes and rehabilitation. They ask questions during it, and then afterwards we have a patient and a partner who also participate who have already been through the experience to answer questions. At the end, we have a kind of a discussion and that's how it ends. We ask patients and partners to evaluate the seminar every month. I should mention that we have been streaming it to Midland, to patients there for the past several months. We are trying to kind of expand the availability.

Scott Redding: How is it determined what kind of a patient partner is there to answer the questions? You know, is it someone that's more recently, someone that maybe is a few years out of care? How you determine ...

Dr. Daniela W.: Realistically, it's somebody who volunteers.

Scott Redding: Okay.

Dr. Daniela W.: And it has to be somebody who's probably quite a few months out so that they've sort of come to terms. They've also seen some recovery, they've had enough experience to share it. Somebody who's objective enough to



understand that the people he's talking to are anxious. Nobody knows how they going to come out, and so you can't be insisting on your own experience too much, you just really give very general bits of information but it's based on experience.

Scott Redding: Do you find that at the seminars that it's more the partner doing the questions and the asking, or do the men actually really engage a lot?

Dr. Daniela W.: It's really both. Both the men and the partners ask questions, which is great because I think people really recognize that it's helpful to them and they know what to expect. It really mitigates the anxiety and the feelings of loss afterwards when they realize they're coping with these side effects when they kind of have a road map.

Scott Redding: Well, the seminar seem to be really great presurgical. What is there, you mentioned earlier that you're also there post-surgery too. Can you explain a little bit more what you mean by that?

Dr. Daniela W.: Yes. The seminar simply prepares men and their partners for the side effects and for how they might react to them. Afterwards, you know, every man's experience is different. About six weeks after surgery, in the program, the patients and partners are invited to meet with a nurse practitioner or a physician's assistant and with a sex therapist. The goal is to assess how the side effects are evolving, how the person is improving or not, what problems there are to solve, or the people have the right kind of information and whether they understand the information that they get. Oftentimes, we are reassuring people because they actually recovering as would be expected, even if they may be in a panic about the leakage and so on. We also, again, provide them with the realistic expectations.

The other thing that we attend to is the emotional state about it all because people have very strong emotional reactions to these changes in functioning, which are quite profound. Some people respond with tremendous sense of grief and loss. Other people are kind of very matter of fact and realistic. There are questions that partners might have about how to help the men or what's relevant for them. We try to address all of those things, because for people to engage in rehabilitation, they have to be emotionally ready to do it. The research shows that if you just offer men, for example, erectile aids, they don't use them or they try them and don't use them. People need a lot of support for engaging in sexual activity that is assisted and they have to understand why they are doing it and how that fits into their overall recovery. We try to do that to help men and their partners to feel kind of emotionally supported, not overly upset about what's going on, having realistic expectations and also to reengage sexually if that's important to them.



Scott Redding: Now, you've mentioned a few times that every man is different, but is there kind of a set timeframe of when you look at where people should be in their recovery from a milestone?

Dr. Daniela W.: Yes. You know, when people come to us about six weeks after surgery, we expect them not to be doing well in anything. But, many of them are already recovering bladder control at that time. Some are recovering erectile function. The first year is probably quite informative. Certainly about incontinence, over 90% of men should be using no or one pad per day for incontinence by the end of the year. When it comes to erectile function, that can take two or more years for recovery depending on baseline function, age, nerve-sparing surgery and so on. But, there are some indicators, of how the recovery is going in the first year.

Scott Redding: Some of the men that maybe are concerned of, okay, I'm just going to be incontinent for the rest of my life. That's not necessarily true and, in fact, probably majority should be okay within a year or so?

Dr. Daniela W.: Yes, they should expect to be pretty much dry. One of the things that I should mention is that four weeks after surgery we send all men to physical therapy for pelvic floor rehabilitation. It tremendously helps with the recovery of bladder control and we encourage men to exercise the pelvic floor for the rest of their lives.

Scott Redding: Talk a little bit more about the pelvic floor rehabilitation.

Dr. Daniela W.: Yes. The pelvic floor supports the bladder and supports the prostate when it's still there. After the surgery, when the bladder neck may not be as strong as it used to be, the valve in the pelvic floor or the pelvic floor helps support the bladder and hold the continence in. Men are encouraged to do exercises to strengthen the pelvic floor, and sometimes to relax some of the muscles because they could be overly tight. Physical therapists are uniquely equipped to assess the functioning of the pelvic floor and help men have a well toned pelvic floor for that purpose.

Scott Redding: Then, what other kind of rehabilitation would men potentially need to focus on?

Dr. Daniela W.: I just talked to you about the incontinence. For sexual rehabilitation, we encourage men to create blood flow in the penis to keep the tissues of the penis healthy, and also to stretch the penis because it tends to shrink a bit after surgery. We do that by encourage them to use vacuum devices. We encourage them to take medications. We call the PDE5 inhibitors like sildenafil to help with the blood flow, and we encourage them to stimulate to orgasm to keep the sexual response going. That is something that remains available to men even if they don't have erectile function.



Scott Redding: Would you say patients that go through this kind of, I hate to use the word regimen, but we're talking about rehab.

Dr. Daniela W.: Yeah, it is a regimen, it's rehab.

Scott Redding: But, that they go through this process, potentially have a much better longterm outcome compared to maybe patients that don't go through a similar type of a program.

Dr. Daniela W.: For the incontinence, there are some trials that have shown that it improves continence early, so it helps with achieving continence status earlier. Penile rehabilitation, as we call it, doesn't necessarily help men recover erectile function, but it keeps the tissues healthy while they're waiting for any kind of natural response to return. It also helps them remain engaged in sexual activity because they attending to their sexual function. The stretching can be important because if you're leaving any organ in the body unattended, it tends to atrophy. We want to make sure that men, A, if they want to have a penis that's either normal length or close to their usual length, that we give them every opportunity. Then also, if they want to be sexually active maybe a year from now that they doing everything they can to keep the penile tissues healthy.

Scott Redding: You know we, again, talk about the rehab side of stuff, but by having them be engaged in these things, does that also help with their emotional state too?

Dr. Daniela W.: Yes, we believe so. Yes, it absolutely does. You know, one of the things that prostate cancer used to be known for was that it was the end of sex life, and it no longer is because men can learn how to create erections using, vacuum devices, injections and so on and so forth. Later on, even sildenafil and other PDE5 inhibitors, so they can recover erectile function even if it's assisted, and men and partners can learn how to be sexually active in this new setting.

It sometimes means overcoming barriers because people complain about sort of the feeling of loss above spontaneous sex, because sex becomes unspontaneous and sometimes they feel like sex is too much work when they have to use sexual aids. We tend to say to them, "Look, in a way, spontaneity is replaced with anticipation. You can have dates where you know you're going to be making love and you can plan for them and plan something fun," and think of them in that way. Many couples, I would say if they are guided and supported, do do that. And for some men, sexual erectile function recovers after a year or so, or sometimes even sooner, and that becomes encouraging to them, and that way they no longer have to worry about losing their sex lives.

Scott Redding: We focused a lot on prostate cancer, and I know the program is a prostate cancer survivorship program, but I got to assume that these are also issues and concerns for other urologic cancers like bladder cancer and testicular cancer.



Dr. Daniela W.: They definitely are. Bladder cancer patients, if they are men and the majority of bladder cancer patients are men, often lose their prostate or right along with their bladder if they are treated with a removal of the bladder. They experience similar things as prostate cancer patients, so that is very relevant for them. For them, there's an additional issue that if they have a urinary diversion, which is like a stoma on their belly, they might deal with other issues related to body image and certainly would benefit and do benefit from support.

Some of the bladder cancer patients are women and they, if they are treated with a cystectomy, if they lose their bladder, often they lose their uterus and their ovaries, which throws them into menopause and for some of them that would be premature menopause, so they have to cope with those side effects, and again, benefit from education and support. In testicular cancer, those are often in younger men so infertility is an issue as well as body image from the point of view of losing a testicle and then having to decide whether to have a prosthesis or not and sort of questions about erectile function. Absolutely, really if I could be as broad, almost any cancer treatment results in some type of at least temporary sexual side effect, and support is critical for people recovering their sexual relationships well.

Scott Redding: So far, we've talked about what we currently are doing, and you've mentioned about research showing certain effects for treatments and recovery for patients. What's kind of the future look like and what kind of research is being done right now for prostate cancer survivors?

Dr. Daniela W.: Much of the research that is being done in the world that I live in is psychosocial support. There has been a lot of research done on reversing erectile dysfunction, for example, so that's its own world. What we in the psychosocial world have discovered is that it is important for men and couples to receive support for the emotional side effects, for the sexual side effects, for just kind of getting through the difficult time of entering survivorship, even in the longterm. I work in the realm of sexual health. In the realm of sexual health, we have been developing interventions to support men and couples. We have found that couple interventions tend to be perhaps more effective, even in supporting men themselves, and so much of the research is going into that.

One of the frustrations in survivorship is that sexual health support is really not available in most practices that treat men for prostate cancer. In my own research, I was able to get funding with a group of experts around the country to develop a web based intervention to support men and partners in prostate cancer survivorship so that they can recover their sexual relationships. We have a program here, wonderful program, The Center For Health Communication Research, that has been the technical arm of this research project. We started in 2015. We developed the intervention, we tested it in six institutions around the



country, and now it's becoming available to many Michigan and to patients in those six institutions.

Next year, the Movember Foundation hopes to roll it out nationally. That means that men, wherever they live, and their partners will be able to access this intervention which basically starts pretreatment and goes all the way to 12 months after treatment. They can access it as long as they have internet. What I should mention is that this intervention is tailored to treatment type, so men treated with radiation, men treated with hormonal therapy, we'll also have their content there. It's tailored to sexual orientation, so both gay and heterosexual men can access it, and it's also tailored to partnership, so there's content there for single men as well as men in partnerships.

Scott Redding: How does this current research play into the clinical care as well? I mean, obviously this web-based program, it sounds very similar to the seminar, but how does it all fit in together?

Dr. Daniela W.: I would say that we see as part of our mission to conduct research to understand what the critical issues are in survivorship and to develop interventions, you know, our own clinical interventions that are evidence-based, and for that purpose we conduct research to make sure that we stay on the cutting edge and that we are kind of where we should be. We have a number of projects that we are working on here. Just to give you some examples, there are a couple of faculty that work on different projects on mindfulness meditation, one to help patients with prostate cancer and then partners with the stress around the surgery. Another one to help men with anxiety while they're active surveillance.

We have a project where there's a way of trying to understand the need for the implementation of low value hormonal therapy for prostate cancer patients who are obviously perhaps not benefiting. We have a project that we are developing with another institution on women sexuality in bladder cancer, and another one on partners of men with prostate cancer. We try to understand the whole field, in a sense, as much as possible from the point of view of understanding that survivorship support is important, that survivorship care is important. That is not just about curing the cancer, although obviously it is that and that patients and their partners benefit when we offer them interventions that are based on evidence.

Scott Redding: What's kind of the average participation? I mean, is it determined, again, by volunteers? You talk about the patient coming in and talking to the seminars. Is it volunteers or is it, you know, are there certain elements like, because it's not a typical clinical trial, what would you think in a clinical trial where you need to meet certain criteria, how is it determined with participation in these interventions?



Dr. Daniela W.: You know, obviously all these participations are voluntary, and I would say, I can only speak really for my own research. Typically in sexual health research in cancer, the participation is anywhere between 33 to 38%. In this most recent study, we've had over 40% participation. This has to be people who are, number one, interested in sexual recovery. Number two, are willing to participate in a trial. Many people we have learned participate because they feel strongly they want to help other people, and then at the end they realize they derive benefits for themselves as well.

Scott Redding: Well Daniela, it's been a great treasure trove of information, I think, for many people with today's conversation. As we wrap up here, what is the big takeaway that you'd want people to know?

Dr. Daniela W.: I think perhaps the most important thing is that people should be educated about the side effects of cancer treatment. My area is sexual health but there may be other side effects, so that they can anticipate how they going to react, how their bodies are going to react, and then secondarily they should be educated, what kind of rehabilitation is available and where they can get it. Because, that kind of support is critical to their quality of life.

Scott Redding: Great, well, thank you again.

Dr. Daniela W.: It's a pleasure, thank you.

Scott Redding: Thank you for listening, and tell us what you think of this podcast by rating and reviewing us. If you have suggestions for additional topics, you can send them to cancercenter@med.umich.edu or message us on Twitter @UMRogelCancer. You can continue to explore the 3Ps of Cancer by visiting rogelcancercenter.org.