

Hi, my name is Becky Campbell, and I'm senior manager of medical content here at PCF. I'm delighted to be joined today by Dr. Stacy Loeb to discuss her recent publication in the journal *European Urology Oncology*. It describes a new survey that will ultimately be used to address sexual health concerns the female partners of patients with prostate cancer may face.

So Dr. Loeb, thank you so much for joining me to discuss this important work.

Thank you so much for the invitation.

So just by way of introduction, Dr. Loeb is a professor of urology and of population health at NYU Langone Health and the Manhattan VA. She is a double board certified in urology and in lifestyle medicine, and is an internationally recognized expert in prostate cancer with more than 400 peer reviewed published articles and 11 book chapters.

Dr. Loeb frequently lectures on prostate cancer, lifestyle medicine, and digital health, and hosts the Men's Health Show on Sirius XM 110 Satellite radio. So, Dr. Loeb, congratulations on this publication. Before we get into the survey, in general, can you tell us a little bit about how the partners of patients with prostate cancer might be affected by the by the disease and its treatments?

Yeah, for sure. So, you know, people have actually referred to prostate cancer as a couples' disease just due to the significant impact that it can have for the whole couple. and some of it relates to the different kinds of sexual changes that can occur, both from diagnostics and treatments for prostate cancer. For example, probably the most widely discussed would be erectile dysfunction, which can occur with many different forms of prostate cancer treatment.

But actually there's really a range of other things that can happen, including things like penile shortening or curvature, changes in libido. ejaculatory changes, etc. and so the impact can be quite significant. And many couples are struggling with coping with some of these changes.

So thank you for that overview and just laying out the background. So knowing that, what did you see as the unmet need or additional work that that needed to be done that inspired you to undertake this survey?

The real inspiration is just the fact that many of the sexual changes that can occur with prostate cancer treatment. There's been a lot of research into the impact of these for the patient and their quality of life, but these also do have a significant impact for their partners. We have a collaborator who has a grant and has been studying the impact of prostate cancer treatment on quality of life for gay and bisexual couples.

So we decided to study the impact for female partners of patients with prostate cancer and their sexual quality of life.

So your paper includes details on the really rigorous methodology, of how you developed the survey. Can you tell us at a very high level about that process?

Yeah, absolutely. So we thought it was important to actually have a survey or some kind of tool that could measure sexual quality of life in female partners of patients with prostate cancer, including some of the specific challenges that they face. And the process of survey development and validation is definitely, pretty technical, but a high level view is that, first, we really did some preliminary qualitative work to really get some detailed perspectives on the lived experiences of female partners of patients and all the different ways that it had an impact on their sexual quality of life, as well as some of the challenges that they were facing, for example, challenges communicating with their partner about some of the sexual changes that were occurring.

So we took that data as well as a literature review and a consensus process with experts and in related fields like urology and sexual medicine. And we used all that to develop a draft questionnaire that could really ask questions related to all of the different themes that were raised in the preliminary work. And then we went through this process, first doing cognitive interviews with the questionnaire, which is basically just having a bunch of people from the target audience go through the questionnaire and describe, you know, how they interpret the questions to make sure that, you know, everything makes sense and that all the response choices, that someone may, may need are there.

And we use that to basically refine the questionnaire down to the final candidate items. And then we sent that around to 200 female partners from across the U.S. to perform this validation study. And there's a lot of complicated math that goes behind the survey validation. But, you know, to suffice it to say that, you know, it was found to be valid, in this sample, female partners from across the U.S.

So now we do have this final questionnaire. I could share my screen for a second here. and just to basically show you how we ended up, after this mathematical process, the questionnaire was basically streamlined down to 19 questions that fall into these seven different domains. So the domains were distress, satisfaction, loss of connection as a couple, doing communication, discomfort with communications, frustration with sexual counseling from clinicians, expansion of the sexual repertoire, and non penetrative sexual activity.

And these seven domains really capture the essence of what was affecting sexual quality of life in the partners of patients. So all of these 19 questions were ranked, the same five point scale from not at all to very much. And depending on the way the question was worded, they were all scored in such a way that higher scores would indicate worse symptoms.

So when you finish the 19 questions, the higher your score was total. Summing them up across the entire thing, that means worse sexual quality of life.

Incredible. It sounds very like a very comprehensive process. I'm sure it was quite a team effort. So can you give us some examples of questions that were ultimately included and maybe tell us a little bit about some of the responses and what that indicates about the experiences of the respondent?

Yeah. So questions could be something like, you know, I feel uncomfortable discussing with my partner the sexual changes that have occurred since prostate cancer treatment, or I'm frustrated with the lack of counseling I received from clinicians about the sexual side effects prior to treatment. So those are just a couple of examples.

And then after those items, the partner could respond. Anything in this range here from not at all to very much to indicate how, how much their feelings align with the statement that was made in the question. And so, you know, I think what was most striking is just how many partners are grappling with the issues on here, real, you know, feelings of isolation, many people feeling like it's changed their connection as a couple.

But also some positives. You know, we do see some people who had better sexual quality of life than others because they did expand their sexual repertoire. For example, some people, you know, met with a sex therapist or tried alternate types of sexual activities or non penetrative sexual activity. Some people were very satisfied with hugging and kissing and other forms of intimacy.

And so it was very interesting to see some of the factors that could be, you know, negative or positive in terms of really coping and adjustment to the new normal that occurs after prostate cancer treatment.

Well, that's so hopeful in a way that obviously many patients or partners are struggling, but there are some that have maybe used some resources and, and been able to adapt to the changes. So you know that it's not all bad news.

So now that the survey is out there in the public domain and is published, how do you see it ultimately being used with, with partners and patients?

I think there's a lot of ways. First of all, we really want to make sure that this is publicly available. So we collaborated with the Prostate Cancer Foundation to create a website, which is housed on PCF.org to house a copy of this survey so that really anyone could actually download it. So, if you, for example, are listening to this and you or someone you know is a female partner of a patient with prostate cancer, you could actually, download the questionnaire off of the PCF website and take it and see how you score, compared to other people.

And I think that, that could be informative and is something that is worth discussing with your doctors. And if you do find that you're having high scores indicating worse sexual quality of life, then there are many potential action items.

So in that same area of the website on PCF.org, we also include, an area with sexual health resources for patients and couples and really highlighting that there are all types of providers who can help with these types of issues, ranging from sexual medicine specialists.

And it's very important to note that this is a very different discipline within the field of urology than oncology. And so, many people may feel that they are not getting a lot of sexual health counseling from, you know, an oncology provider. But sexual medicine is a different fellowship with a different certification. And, and so there, there is, a tool to help find a sexual medicine specialist.

There's also online tools to help find sex therapist and sex educators in your area. If the problem is more in the line of grief or isolation, either individual counseling or couples counseling may be helpful. And so we hope that by people taking the questionnaire, it can help them to identify which of those domains, maybe they're scoring higher or worse scores in order to help find the kind of assistance that they may need to improve their quality of life.

And Dr. Loeb, thank you so much for that very comprehensive answer about resources, because that's really what it's about is taking a questionnaire, finding that questionnaire on PCF.org and then taking those next steps depending on what they and their doctors discover as a result of that discussion. So thank you for that. So in closing, do you have any additional research planned on this topic or in related areas?

We do. You know, I think first of all, we're very interested in partnering with our colleagues who are working on more research with gay and bisexual couples and hopefully adapting the questionnaire to male partners of patients with prostate cancer. Also, interestingly, we're seeing that this work is actually relevant to some other conditions that we treat in urology.

In fact, we have some preliminary qualitative data with my collaborators at Memorial Sloan Kettering looking at patients with Peyronie's disease or penile curvature. And their partners actually expressed many of the same themes in the qualitative research as the partners of patients with prostate cancer. So it's very neat to see that some of this work that we've been doing in prostate cancer may actually be relevant and helpful to couples who are facing other kinds of sexual health conditions.

And so we may also try to adapt the questionnaire for partners of patients with different kinds of sexual conditions.

Wonderful. That's such good news that this work will go on to help other types of populations. Well, Dr. Loeb, congratulations once again. And thank you for taking the time to expand this, this research with us.

And, we'll have a link in the show notes to the website. thanks again for taking the time. And congratulations.

Thank you.