

Sexuality & the Cancer Patient

Webcast

July 15, 2008

Leslie Schover, Ph.D.

Please remember the opinions expressed on Patient Power are not necessarily the views of M. D. Anderson Cancer Center, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.

Pamela's Story

Andrew Schorr:

Hello and welcome to Patient Power, sponsored by M. D. Anderson Cancer Center. I'm Andrew Schorr. This is where we connect you with leading experts in cancer and always inspiring patients. So often we've talked about specific cancers, but there are some overriding issues that affect most all cancer patients somewhere. We've talked about fatigue in cancer, but a very other important issue is sexuality in the cancer patient for men and women. And I know for me as a leukemia survivor when I was dealing with the leukemia not only being worried about my mortality, going through the treatment, being just tired, I can tell you that sex was not at all on my mind. And I think with all the anxiety, worry about the cancer it wasn't on my wife's mind either. How did we get back to a place of having enjoyment of sex and having that be a part of our life, which it should be for anyone, hopefully? Well, that's part of our discussion today.

I'd like you to meet Pamela Lewis, who coincidentally works at M. D. Anderson. She's a breast cancer survivor, and it happened as a younger African-American woman. Pamela, if I've got the story right, you were working at M. D. Anderson dealing with women with breast cancer where it often happened earlier and so while some recommendations have been have a mammography at 40 in African-American women often it's recommended earlier. At 36 you did, and it ended up eventually after a biopsy showing you did have breast cancer. Is that right?

Pamela:

Yes, that is correct. However baselines are recommended for all women, and if you have a tendency to have a history of breast cancer in your family you may want to look into a clinical breast exam prior to age 35.

Andrew Schorr:

Okay.

Pamela:

Yes, I was diagnosed at age 36.

Andrew Schorr:

Oh, my. So fortunately you were treated successfully with lumpectomy and radiation, but single woman, that brings up lots of stuff as being a breast cancer

survivor as far as your body image now, as a lumpectomy but you had radiation, maybe there were changes after that. Has sexuality been something you've really had to work through?

Pamela:

Yes, it was something you have to work through because especially after the surgery you're very sore and if you are in an intimate relationship you have concerns with someone touching you, seeing your scars, applying too much pressure to you if you're simply hugging. Those are concerns that you have about hurting your body or your body image as a woman.

Andrew Schorr:

And related to intimacy, I imagine even if you're dating whether you disclose or when that you've had surgery for breast cancer, you're a cancer survivor and all that has issues that weigh on intimacy.

Pamela:

Yes, it does weigh because in the back of your mind you're wondering if the person a going to accept you if you tell them that you are breast cancer survivor. I at first did have some concerns with telling my partner or telling people that I dated afterwards that I was a survivor because concerns came up with how I feel about certain points of intimacy or foreplay, and what areas did I feel comfortable with a man touching me. And most certainly the breast is one of the areas where women may not always feel comfortable with caressing, and if you have surgery with scarring, or if after radiation one side of your breast is darker than the other, then there are going to be some questions. So you have to decide when you come to a point when you're going to be intimate with an individual. You don't want to wait to that point to tell them, "Hey, look, I'm a breast cancer survivor. I want to tell you about the scarring that I have." I think when you get to the point in your dating relationship and when those kind of concerns come up, not just prior to the sexual act or the intimacy, but beforehand, you need to let them know that you are a survivor, what areas you feel comfortable being touched and how does it feel.

Andrew Schorr:

Well said. Now, I want to mention of course there are issues that come up for men, and we'll discuss this in this program as well. And also related to this but different are fertility issues, and I know in your case, Pamela, you look forward to having a child, and those are issues for someone who is being treated for cancer or a cancer survivor who has had various therapies as well. We'll discuss that in a future Patient Power program, but we're going to focus on sexuality and intimacy today.

It just so happens that Pamela works with one of the world experts in this area, and that's Leslie Schover, Dr. Leslie Schover, who is professor in the department of behavioral science at M. D. Anderson. She's written pamphlets for the American Cancer Society, she's written books about sexuality and the cancer patient for men

and for women. So, Pamela, it's actually a good thing that you get to work with her in her research there and you assist in that because you're actually sort of living the process of helping men and women with these issues, aren't you?

Pamela:

Yes. It is a great experience working with Dr. Schover. She was actually a great resource for me after I was diagnosed in offering some suggestions on fertility as well as just getting your sexual being back to life. And she has, as you mentioned, pamphlets and books that she's written. One of the pamphlets that she's written was key to my research project I'm coordinating for her, and I actually read that pamphlet which is geared towards African-American women.

Addressing Sexual Issues

Andrew Schorr:

Well, we're going to learn a lot more about it. Let's meet this renowned expert, Dr. Leslie Schover. Dr. Schover, thank you for being with us. So it's kind of close to home with Pamela dealing with these issues, but you see people every day. During your research you've interviewed I'm sure hundreds if not thousands of people affected by this. These are big issues, but when you're diagnosed with cancer, I know it was for me, I'm sure for Pamela, most all our listeners, the first thing you want to do is be cured or at least beat back the cancer, and sexuality is not at the top of your mind. But as time goes on for you and your partner, or potential partners of course, it's there and looks like it's got to be addressed.

Dr. Schover:

Well, thanks for your kind introduction, Andrew. I think that what you're saying is true, but remember that some kinds of cancer treatment involve things like removing the prostate or removing the bladder or the rectum, and those kinds of surgeries for example have a very direct effect on sexuality. And for some men or women thinking about having that kind of surgery and thinking about the choices between different kinds of cancer treatments, sometimes sexuality is close to the top of the list right after survival.

Andrew Schorr:

You're right. I think of it as a leukemia patient where it didn't involve any sexual organs, but you're absolutely right, and so those are key choices. Now, sometimes though they kind of get discussed really quickly by the oncologist or the surgeon, and maybe it hasn't fully hit home about the significance of the decisions we're taking with different treatment options.

Dr. Schover:

Well, I think that the oncologists try very hard to do a good job, but they are under such pressure to see patients in a short amount of time and they have so many different issues to discuss that it's difficult for the doctor and the patient to take

enough time to really focus on the details of what could happen. I often recommend that somebody in our site-specific cancer clinics, like PA or an advanced practice nurse or an oncology social worker, become really comfortable with the kind of treatments in that clinic and their sexual side effects and that they take some time to really sit down with a patient and possibly his or her partner as well and really have that longer discussion.

Vaginal Dryness

Andrew Schorr:

Okay. Well, let's think through this then. In some of the cancer treatments then there is a direct effect on sexual organs or proximity with sexual organs that need to be considered going in. And then there are drug therapies, sometimes systemic therapies that will make a difference, for instance putting a younger woman into menopause which could lead to issues there. Certainly you mentioned about prostate cancer, other urinary type surgeries for men that can affect nerves and erectile dysfunction, lots of things like that. So that needs to be considered. As someone makes choices related to therapy then there are options. We talked about fatigue, and that can be dealt with. We'll talk about other issues of anxiety or depression or pain, and those can be dealt with. And then there are also treatments to help. Like a big thing for women might be vaginal dryness, right?

Dr. Schover:

Yes.

Andrew Schorr:

What do we do there? Let's take that one for example.

Dr. Schover:

Yes, and I think you had a question from one of our listeners about that.

Andrew Schorr:

Yeah, that's right. Let me get to that. You're so right. We did get one. Well, there was someone who wrote in about concern about pain and vaginal dryness and she's a breast cancer survivor. What do you do about that?

Dr. Schover:

Well, you know, I think it's a lot more treatable than women often realize and what upsets me is women often just don't get the very specific instructions that could help them. For one thing, most of the dryness has to do with being put into a sudden menopause, and that has more severe symptoms than just going through natural menopause, and that's especially true for women who weren't menopausal to begin with and then typically either because they have a strong dose of chemotherapy or they have radiation to the pelvic area or their ovaries are both removed, they go into a very sudden menopause with lots of hot flashes and

disturbed sleep and vaginal dryness. But also women who were menopausal and some of whom might have been taking estrogen and then have breast cancer and are told not to take it anymore go through something quite similar.

And the problem is that without estrogen which is made by the ovaries the vagina actually shrinks, and the lining, which is like a mucous membrane kind of similar to the lining of your nose and mouth, gets very dry, and with intercourse you can actually get little tears in the lining and even spotting of blood afterwards. And once a woman has had that experience, that intercourse really hurts, it often reduces her interest in being sexual. So things you can do: One is that it's very important to use extra lubrication, and there are nice lubricants now that are either water- or silicone-based that don't have any perfumes to irritate the skin and that are thin and watery, more similar to a woman's natural lubrication, and they don't dry out as fast as the old gel lubricants that used to be the only thing around.

So it's important not to just put that on in the bathroom and come out and pretend you didn't do anything because a lot of women are embarrassed and feel like it's not natural to have to use a lubricant, but rather make it part of your foreplay, and when you and your partner caress each other put lubricant on your fingers and make sure if you're going to have intercourse with penetration, that you include the area around the vaginal entrance and the area, if your partner is a male, around of the tip of his penis. If both partners are very well lubricated penetration doesn't hurt and isn't tight and dry. In addition there are other products that are called vaginal moisturizers that you're supposed to use several times a week, and they're usually some form of gel, and they can also help. So I think a woman should use a moisturizer which sometimes can take a couple of months to get its full effect and then use extra lubrication every time she has sex.

Andrew Schorr:

Dr. Schover, let me ask you this. Now, Pamela, your breast cancer, when they looked at what type of tumor it was it was estrogen receptor positive, right?

Pamela:

Yes.

Andrew Schorr:

Okay. So, Dr. Schover, for women who learn about that in breast cancer they know that estrogen is the fuel for the cancer cells, yet there are some very low-dose estrogen creams. What's your view of that, or does that vary at M. D. Anderson?

Dr. Schover:

I think often what's confusing for women is that their gynecologist will say, Oh, this dose of estrogen is so low and so little escapes from the vaginal area into your bloodstream that I think it's worth the quality of life improvement, but their

oncologist may say, No estrogen is safe and I really would rather you didn't take this. So each woman has to decide for herself, and that's why I think it's important to try the more conservative treatments first, and if they don't work then go to estrogen.

Another thing women can do before going that far is to learn to relax the muscles around the vaginal entrance because sometimes tension and anxiety contributes to the tightness. And they can do that sometimes by using a set of vaginal dilators which are kind of little silicone tubes that come in graduated sizes, and you can get them from your doctor or even order them on the internet and just use them in private and get confident that you can have something first rather small and then larger in your vagina.

But if all those things don't work, yes, there are two types of estrogen that probably have the lowest escape rate into the bloodstream. One is the Estring, which is like the ring of a diaphragm without the rubber cup, and it stays in for three months and releases a very low dose of estradiol, which really does wonders for the vagina. And after the first week the vaginal lining kind of thickens up, and some escapes into the bloodstream but similar to what a woman in natural menopause might have in terms of levels. The other is a suppository that melts in the vagina and does a very similar thing.

And some oncologists have warned that with the suppository in particular that the levels in the bloodstream for some women are high enough that if they're taking one of the newer drugs, the aromatase inhibitors, like Femara is one of those, that it might overwhelm the good effect of those drugs. So again it's very individual. A woman might need to have some periodic blood tests and work closely with her oncologist on that.

Andrew Schorr:

All right. We're going to take a very short break, and when we come back I want you to comment on some of these products that are advertised both for men and women and how to make sense of that. And also some comments about testosterone, another hormone and what your feelings are on that. This is all coming your way as we continue our discussion on Patient Power brought to you by M. D. Anderson Cancer Center. We'll be right back.

Andrew Schorr:

Welcome back to our Patient Power program sponsored by M. D. Anderson where we're talking with really a world-renowned expert, Dr. Leslie Schover, who is a professor in the department of behavioral science. She's a clinical psychologist. She has years of training as a sex therapist, combines a lot of expertise to help people. She's at M. D. Anderson. And also someone who works with her as a

research coordinator and as a breast cancer survivor, thought about these issues herself, that's Pamela Lewis. And we're talking about sexuality and the cancer patient, and we'll talk about fertility issues in a future program.

Dr. Schover, so where we left off, we talked about various approaches and even low-dose estrogen for women who maybe have some vaginal dryness related to therapy that they've had. What about, you know, there's no shortage of products that are advertised on TV or in the newspaper or even at the pharmacy where sometimes there are big claims but not the data. Should we spend our money on those?

Dr. Schover:

I don't think so. I always tell people that if someone found a true aphrodisiac, an herb or a vitamin, or a drug that would increase your desire for sex, which is a problem for men and women often after cancer, that they would have their own office building or maybe their own city or country, and we'd all know about it. And the fact that you have to advertise these products testifies to their lack of effectiveness.

Andrew Schorr:

Right. I agree. It would be lining a cure for baldness would be front news for men like me.

Dr. Schover:

You said it.

Testosterone Treatment

Andrew Schorr:

Well, let's go on. One of the things that's in development though is we talked about estrogen but we've also been hearing about development of testosterone. What's your view of that, whether that should be approved and be offered to help people with these concerns?

Dr. Schover:

Well, testosterone has been available for many years, but recently the drug companies have developed easy to use forms like gels that you just rub on your skin or patches that you can wear and these are being used by men. Unfortunately some physicians prescribe this for men who truly have normal testosterone but they may be in their middle age and they're overweight and don't exercise, and they have some difficulty with erections and sexual desire, and I think it's very over prescribed, but it's become a big business.

So they've also been pushing the idea of testosterone for women, and there was one drug that Procter & Gamble had in development that wasn't approved by the

Food and Drug Administration because of a lack of safety studies. And there are now several other versions in the pipeline, and I'm very concerned because I think there's very good evidence that testosterone is more closely linked to breast cancer risk in women than estrogen or estrogen plus progesterone. Now many women have stopped taking those hormones after menopause even though estrogen could help their symptoms, but they don't realize that testosterone is maybe more dangerous. And I think the evidence that it really does something for women's sexual desire is really poor. There are now three studies in breast cancer survivors showing that there's no relationship between their own testosterone levels and their reports of sexual problems, but what does relate to sexual problems is having a bad relationship.

Urinary Incontinence

Andrew Schorr:

Right. Well, there's so much to talk about. Let's give men some equal time. Here's a question we got in from Kenneth in Houston. He says, "I used to think about sex almost too frequently. Post cancer treatment I think much more about urination, leaking, and just going to the doctor and the schedule." And he said he actually has to plan to have sex with his wife. He's taking Cialis in advance so he's planning things, but he says the pleasure is out of it. So he says "How can I look forward to sex with my wife when I'm fearful she'll touch me and get a handful of dampness," as he says. So he's very worried. How does he work through that fear?

Dr. Schover:

Well, it sounds like he probably had his prostate removed in surgery, and one of the really common side effects in the short term, and luckily for most men it gets much better over time, is lack of control over urination. But many men will say that when they get sexually excited even if they're dry all day that they do have some urine that leaks out of their penis, and it makes them feel very bad about the odor and whether their wife will feel comfortable touching them, much less having oral sex.

One thing that you can do is be sure not to drink a lot before you have sex and to empty your bladder beforehand and keep a wet wash cloth with some nice scented soap or something right by the bed so if you do leak a little bit you can just wipe it up. Or you can wear a condom during sex if your erections are reliable. Or sometimes couples if they have available a nice large shower or a hot tub or something they might be comfortable having part or all of their sexual encounter in that environment where they aren't even going to notice.

If he's able to use Cialis and is successful in getting firm erections, it may seem like work because you have to plan but he's lucky on the other hand because a lot of men after cancer surgery just don't get firm enough erections with the oral drugs that we have available for it to really be effective. And what I find is that most men

are willing to try one of the oral medications that you see advertised on TV, and if you only have a mild erection problem that often works really well. But if it doesn't give men a firm erection, Men are much more reluctant to try the treatments that are more effective like using a tiny needle to inject medicine into the penis to get an erection or using what they call a vacuum device which is like a little pump you put over the penis. You pump the air out and it creates an erection. You maintain it by slipping a band around the base of the penis. And then the most extreme is to actually have a surgery where they put a little bionic pump inside your body and you have a bionic erection with a penile prosthesis. And that surgery actually can work extremely well but many fewer men have it now because they're monkeying around with all these other treatments, many of which work for a while but they're such hassles that men give up on them.

Andrew Schorr:

Right, and that brings us to a good point. First of all we have to understand when we've been treated for cancer, cancer survivor, we may be the same or sometimes a little different from everybody else who is just advertised on TV, take this pill and you're going to be a He-man, a Tarzan, but that's okay. And that you deserve to have intimacy, and that can be defined broadly too and then also a sex life. So it sounds like you need to have an ongoing conversation, whether female or male, with your provider or additional counselors because communication is the key and you deserve this as part of your quality of life.

Communication

Dr. Schover:

Yes, and you know it's so easy for sex to become a big performance and then it's like work. And it's like, oh, my gosh, I have to have a firm erection, it has to stay firm during intercourse, and often what means is rushing into intercourse before the woman is maybe fully aroused and ready, especially if she's past menopause and takes a little longer. And then if sex doesn't work well both partners may have negative feelings afterwards, disappointment, even a little bit of anger at each other, and over time if that's not addressed their sex life can really suffer.

So what I usually advocate is try to forget about making everything perfect and think of sex as a time to share closeness, pleasurable touch, fun, you know, put on your favorite music and put a candle or a low light in the bedroom and just relax about it and enjoy being together because one of the things that cancer teaches us is to enjoy every day because it's a gift.

Andrew Schorr:

Right. That's so true. I want to get back to Pamela in a second, but I just want to make a point that it's a matter--right, it's a matter of communication and it's a

matter of not feeling like you're in a race in defining intimacy and just allowing time for it. I know that really worked for my wife and myself. As I said I got back, got back on track.

Pamela, what about for you? I know you've found certain mentors or friends, more experienced cancer patients, people who have been survivors, someone I know in Sisters Network there in Houston where that discussion and guidance just helped you a lot.

Pamela:

Yes, it did, because you're really afraid, and, as you mentioned before, the mortality issues are persistent on your mind so you're really not thinking about the sex but afterwards you do want to maintain those relationships and that partner that you have present. So getting to the intimacy you have to explore things that--you have to discuss with your partner things that you feel as a survivor. How can this person help you get back in tune with your body, make you feel comfortable with foreplay, caressing, what areas will help you feel aroused. Explore those different parts on your body, let them know what makes you feel good. And I think that's what has really worked for me in my intimate relationship is to be open and honest about things that hurt, things that I do not feel comfortable with, and also asking my partner if he feels comfortable about helping me get back to that point where I feel intimate, where I even feel attractive again.

Medication Side Effects

Andrew Schorr:

Those are such good points. Now, Dr. Schover, one other thing we haven't talked about and that is beyond the cancer medicines, we talked about the effect or the cancer surgery or radiation, the effects of that, could be other medicines were prescribed that could affect basically our ability to, let's say, for a man to have or maintain an erection, could have other effects on a women. So it sounds like we have to have a dialogue with our doctor about that too because sometimes you could be switched to another medicine, right?

Dr. Schover:

Yes. Or, you know, it's really common, maybe even more so for women than for men, that at the time of cancer treatment women are put on drugs to combat anxiety or depression, and they just kind of stay on them for years afterwards without re-examining whether they still need them. And unfortunately those classes of drugs, the drugs to treat depression and a little less so the drugs to treat anxiety, are some of the ones with the most sexual side effects. So switching a type of drug, reducing a dose or after a while trying to see if you really still really need it are all good options.

Also, even when people have advanced cancer they still have a lot of needs for cuddling and closeness and even some sexual pleasure, and sometimes people are in a lot of pain and they might be on chronic pain medications. And any of the medicines that are derived from opium or synthetic medicines like that, like OxyContin or Dilaudid or all those kinds of medicines, also blunt sexual desire. So that's another issue.

Final Comments

Andrew Schorr:

These are so many issues that we've discussed. We've got to do it again, Dr. Schover, and, Pamela, you too.

Dr. Schover:

Yeah, I need a whole day.

Andrew Schorr:

Now, you have research going on at M. D. Anderson now. If someone wants to say maybe what I'm going through that can help with the research. How can they do that if they want to help?

Dr. Schover:

Well, currently we probably aren't going to have a project that's going to need more subjects until maybe a year from now, but we're working on a computerized educational piece for women about sexuality and fertility after cancer, and when we test it we're going to do that with breast and GYN patients. So I'm not sure whether we should really ask people to call in currently.

Andrew Schorr:

We'll just say stay tuned, I guess, for those of our regular listeners with Patient Power. But I just want to go over a couple of key points real quickly, and that is, as we acknowledged earlier, cancer can bring sexual changes, physical, emotional, affect your relationship. Certainly in another program we'll discuss the difficulties with fertility, and of course it can affect your desire, and I mentioned that it really affected mine. For most of our listeners I know if you're really focused you want to beat the cancer, that becomes preeminent and your partner may well be worried about that for sure with you, and these other issues may go in the background. Or the sexuality issues may be part of the treatment, as Dr. Schover said.

There are people at M. D. Anderson who very ready to discuss this with you and so bring it up in your interactions with an M. D. Anderson provider or wherever you may be listening to us. It's important to put it on the table, both related to treatment and then afterwards. And it may also, and I know it worked for my wife and myself, it was very helpful to also have some counseling after cancer therapy where this was part of the discussion.

Dr. Schover, how did I do in summarizing?

Dr. Schover:

Great.

Andrew Schorr:

And, Pamela, any final words from you? You've really given some great suggestions. Maybe what I would ask for you is you're hoping to have relationships and maybe some day a child or two, what's your outlook for the future now as far as intimacy?

Pamela:

I think my outlook is very positive. I just try to stay hopeful, try to enter a relationship with someone with an open mind and to be honest about what's going on with my body and as far as my survivorship and what I expect out of intimacy. I think that's the best thing. And let them know how you're feeling. Seek out like you stated those resources that you need. My gynecologist, Dr. Schover, other survivors, turn to them and ask them what do they feel or what do you have to do to restore that part of your life.

Andrew Schorr:

Well, I think it's great the recovery you're making. I wish you well. Maybe we'll do a program sometime in the future where you'll talk about a new baby, okay?

Pamela:

Yes.

Dr. Schover:

And I can testify that Pamela is a wonderful person. She's beautiful and accomplished and smart with a great sense of compassion for others, so--

Andrew Schorr:

Well, I'll be in Houston for a meeting with the Anderson network folks in September, so, Pamela, maybe we can meet. It would be fun. I want to thank you, Pamela Lewis, for sharing your personal story with us. And Dr. Leslie Schover, professor, Department of Behavioral Science at M. D. Anderson and a renowned expert on sexuality and cancer for both men and women. Thank you for being with us. And all the best to both of you with your research.

Pamela:

Thank you. And we'll see you at the patient conference.

Dr. Schover:

Thank you.



Andrew Schorr:

Yes. Thank you very much, ladies. Well, this is what we do on Patient Power every two weeks. You are welcome to send us suggestions of course, and there's so much more you can find in the Patient Power section of mdanderson.org.

Our next program will be on August 5th we'll be posting it, and it's "Advances in the Treatment of Stomach Cancer," and that's with Dr. Alexandria Phan. I'm Andrew Schorr. Remember, knowledge can be the best medicine of all. You've been listening to Patient Power sponsored by M. D. Anderson Cancer Center.

Please remember the opinions expressed on Patient Power are not necessarily the views of M. D. Anderson Cancer Center, its medical staff or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.