

Living Beyond Cancer

The Short and Long Term Effects of Cervical Cancer

Guest: Dr. Valarie Galvan Turner

Lauren Hixenbaugh: Welcome to Living Beyond Cancer. I am Lauren Hixenbaugh with the West Virginia Cancer Coalition, Mountains of Hope. Living Beyond Cancer is a series of podcasts created for cancer patients, survivors and caregivers. This series is sponsored by the West Virginia Cancer Coalition, Mountains of Hope, and produced by the WVU Cancer Institute's Cancer Prevention and Control. Today's topic is the short and long term effects of cervical cancer, and our guest is Dr Valerie Galvan Turner, an assistant professor and director of Gynecologic Oncology Clinical Research at West Virginia University. And we are so thrilled to have Dr. Galvan Turner here today. And the first thing is, just tell us a little bit about your role at the Cancer Institute.

Dr. Galvan Turner: Well first, I want to say, thank you for having me. My role at the Cancer Center, I am a gynecologic oncologist, so I primarily treat women who have cancer of the female reproductive organs. We do surgeries, we do chemotherapy, we do most treatment from start to finish for patients with gynecologic cancer, including patients with cervix cancer.

Lauren Hixenbaugh: Wonderful. Well, we are really glad to have you as a part of our team and we are really glad to have you here today. So one of the big topics right now is survivorship. So what does survivorship mean to you?

Dr. Galvan Turner: Survivorship is very important and it is not often a big focus as you first get your diagnosis and you're going through treatment. Survivorship focuses on the health and life of a person with cancer after they have completed treatment and until the end of life. So it includes issues related to the ability to get healthcare, the ability to get follow-up treatment, the late effects of their cancer treatments, secondary cancers, quality of life, and just general health maintenance.

Lauren Hixenbaugh: Okay. And you mentioned late effects, so what are some of those short and long term effects that folks with cervical cancer are going to experience?

Dr. Galvan Turner: Well, it really is dependent on the type of treatment that they get for cervical cancer. Obviously, everyone's going to have a different stage of diagnosis, and a different grade at diagnosis. And so each patient is going to have an individualized treatment plan that is going to be designed to give them the best possible outcome. Treatment is not the same for everyone, so some patients may be candidates for radical surgery, some patients will be better candidates for radiation therapy, and so late treatment effects really depends on what kind of treatment you had to start with. With regards to the surgery, short term effects are obviously going to be immediate postoperative pain. But long term effects, late effects of surgery, they can be bladder dysfunction, it can be inter-abdominal scar tissue that will occasionally cause pain and discomfort, there can be fatigue, there can be a condition called lymphedema, which is excessive swelling of the legs, that's often due to removal of lymph nodes, which is an important part of that surgery. It's not often a common effect, but it can be an effect after that type of surgery. There can also be fluid retention and weight gain.

With regards to radiation, both the short term and the long-term effects can be very similar. With radiation, there are conditions in which the treatment can cause irritations within the bladder, the rectum, the intestines, that can cause symptoms like bleeding in the bladder, frequency of urination, bleeding from the rectum or diarrhea.

And those other complications such as skin toxicity, where they can get some irritation of the skin while they are going through treatment. Most of those can be treated during their symptoms and phases. Rarely, they may need additional procedures to help with some of those side effects, but once a patient's been treated with radiation, those symptoms can often recur later in life, when they're far removed from treatment. It's not common, but it is something that can happen and it's often not something that a patient is thinking about when they're 10 or 15 years out from treatment. They may forget to mention to their doctors that they had had radiation, and so it can delay a diagnosis of the cause of those symptoms. Other side effects from radiation can be changes in sexuality, issues with vaginal dryness, or sexual dysfunction.

Lauren Hixenbaugh: Okay, so there's a lot of late and long-term effects there, physically. Is there anything that you feel like patients deal with emotionally after having this diagnosis?

Dr. Galvan Turner: I think the biggest emotional thing as I see with most in all of our cancer patients, it's just the effect of a cancer diagnosis. There's always that concern that their cancer could come back. There's always feeling that they want to see their provider for their surveillance visit, where we check on them after they've completed treatment, but they're also concerned of what we might find, and that brings on a lot of emotional stress and anxiety. Other issues that particularly pertain to cervical cancer can be difficulty with emotional health and sexual health as well.

Lauren Hixenbaugh: Okay. So these patients that are dealing with these long term effects, whether it's physical or emotional, what's the treatment for them? The common treatment, how do they work through these things? What can we do for them?

Dr. Galvan Turner: Everyone has their own individual way of getting emotional support. I think that the thing that we need to make sure that we bring to the forefront of a patient's mind is, that it is okay to ask for support. This is not something that patients typically should deal with alone. If they are getting emotional support from their family, that's wonderful. If they have church group or a community group that they belong to and that's giving emotional support, that's wonderful. But it is also sometimes important to have support from other patients who have gone through the same thing that you have gone through, or a similar thing that you have gone through. Because, there's always that connection there that others just can't understand. That feeling of concern that things can come back, they can share their stories, their gains, their losses and all of those things are important when you are trying to survive this cancer and really bring yourself back to a point where you are living the best life that you can possibly live.

Lauren Hixenbaugh: Yeah, certainly. And there are support groups here at the Cancer Institute for those folks, well for both folks that have treatment here and those throughout the state that may have treatment elsewhere. Living Beyond Cancer does have an online Facebook support group. So you just

hop on Facebook and you search Living Beyond Cancer and it should pop up and you can join the group. We would love to have more members and people start sharing their stories, and really benefit from that resource.

Dr. Galvan Turner: Absolutely. I highly encourage my patients to seek out support groups, and again, we're working towards building our in live person support group at the Cancer Center. Often, I will get some of my patients that say, "I don't have social media." I will ask them if they have a younger family member, and they usually do. And they can be a great resource in helping them to make a Facebook page or learn how to navigate Facebook. Because that's a good way for them to be able to connect to people who aren't nearby.

Lauren Hixenbaugh: Yeah. And family's a huge resource and we talk about one of the frustrations that we hear, is that there's kind of this lack of linkage between the primary care provider and the oncologist often. And I think, I am going to let you talk about it a little bit, but I think the family member is kind of a key aspect to bridging that gap too. But what would your advice be for those patients that are feeling that lack of linkage?

Dr. Galvan Turner: With regards to family members, I completely agree. I strongly encourage patients who come for their first consultation or for big visits where we're going to be planning treatments and things, to come with a friend or family member who's trusted. It is always great to have a second person in the room to hear and write down things for you, because I am going to be focused on the patient and making sure that they understand the next steps. But it is great to have someone writing things down or asking other questions that maybe that the patient's not thinking of. So family is always a wonderful support, but good friends are a good support too.

With regards to sharing this information with your other doctors, this is something that I also feel very strongly about; it is very important. So for our practice here, we always make sure to give patients treatment summaries.

Lauren Hixenbaugh: Oh, that's great.

Dr. Galvan Turner: Which kind of just gives an overview, a one to two page document says, "This is what you've had so far, this is what your diagnosis was." It is very easy if your provider is linked through our electronic medical records system. But a common misconception, is that if your doctor has a computer and an electronic medical record system, they should be getting the information that we have. And unfortunately, not all electronic medical record systems are the same, and they do not all talk to each other.

So within the WVU system, oftentimes you can see notes from other providers and they can see our notes. But for other doctors who are not linked to that system, I do try to send them separate correspondence, but it does not always-

Lauren Hixenbaugh: I can see how that would be confusing.

Dr. Galvan Turner: Yes, it does not always happen in the smoothest way possible, so I do like to give patients important documents about their cancer diagnosis and their cancer treatment. I'll usually tell

them, "I want you to get a folder or a binder, and anything that I give you I want you to put it in there." I will usually tell them around back to school season, to buy some dividers, something small and portable. Because it is also important if they travel, which I love to travel. But if you do travel out of state or to other areas, if you carry your little bit of information with you wherever you go, if you were to end up in an emergent situation, they at least have all the information that they need, with regards to your cancer care.

Lauren Hixenbaugh: Yes.

Dr. Galvan Turner: They are not trying to call over here and get records when it is an urgent situation. So I do encourage patients to also travel with their cancer treatment summary, because it is a good way to give whoever might be taking care of you some important information.

Lauren Hixenbaugh: Absolutely.

Dr. Galvan Turner: The Society of Gynecologic Oncology, which is kind of our group that helps us to make the best practices for women with cancer of the female reproductive organs, they do have a patient site. On that patient site, there's different information about different cancers. And when you click on the cervical cancer link, there is also a link to a cancer treatment summary. So if your doctor hasn't given you one, if your oncologist hasn't given you one, you can print that one from the SGO website, take it to them and have it filled out, and take it back to your primary care doctor, or any doctor that you may want to have that information. It is actually a pretty easy document.

Lauren Hixenbaugh: I was going to say, and what is that website again?

Dr. Galvan Turner: It is the [foundationforwomenscancer.org](https://www.foundationforwomenscancer.org), or [sgo.org](https://www.sgo.org).

Lauren Hixenbaugh: Okay. Great. That's a wonderful resource for patients.

Dr. Galvan Turner: It is. So it allows them to take a proactive approach to their treatment, and give them this one and a half page document and say, "Could you fill this out, so that I can take it to my doctors?" And everyone is on the same page again.

Lauren Hixenbaugh: That's great. Now, are there additional resources that you would recommend for folks?

Dr. Galvan Turner: The American Cancer Society also has a very good website, a lot of good information that's easy to understand. It has links to other online resources and support groups as you said, that tried to link women across the United States. So that's also a good resource for them.

Lauren Hixenbaugh: Okay, wonderful. So one thing I am really excited to add to today's podcast, is we were able to get some questions on Facebook when we announced that you were going to be our speaker today. So the question is from Kristen Sepp. And she says, "As a healthcare provider in the state, I'd be interested in hearing more on one, the prevalence of cervical cancer in our region." She mentions

Appalachia. "And then two, where to refer underserved populations to receive an annual examination with pap smear, as that is the best early detection measure currently."

Dr. Galvan Turner: And those are great questions. So we will start with the first question. So in 2020, it is estimated that in the U.S., we are going to have about 13,800 new cases. So that number's been fairly stable over the last 5 to 10 years. It fluctuates within the 13,000 range. It is a little bit up from the estimates that were in 2018, 2019. But we are still at 13,800. Of those, 4,800 women will likely die from their disease this year.

So we still have a big problem with cervical cancer, and Appalachia and West Virginia is one of the top five states in the U.S. with the prevalence of cervical cancer. So this is an important topic to bring up to our patients, to the communities, that we need to do our diligence and really do our best to try to get everyone screened for cervical cancer.

So when you break that down by numbers, we are looking at, for every 100,000 women, about 9.1 times or percentage of those patients are going to have cervical cancer in West Virginia alone. Various numbers that we are looking at through the Bureau of Public Health and the CDC, they'll range anywhere from 80 to 100 patients per year in West Virginia alone with new cancer. Unfortunately, unlike other states, in West Virginia, over 51% of those patients are already going to be diagnosed an advanced stage disease, which is a very different number than when you are looking at other states across the U.S. Early detection is key, and that will allow us to catch patients at earlier stages when the disease is less aggressive, and the treatments can offer a better chance of cure. So we do have a high incidence of late stage cancers here.

Lauren Hixenbaugh: And you mentioned the word, early detection. What does that look like for people?

Dr. Galvan Turner: So for patients, that would include an annual exam and pap smear screening. So there's often a misconception of what a pap smear is, and what an annual exam. So a speculum exam is an exam that a gynecologist or a family medicine doctor, occasionally internists will do it as well, where they look inside the vagina to visualize the cervix. That is the part of the uterus that you can see when you look through the vagina. That does not mean they are getting a pap smear. A pap smear is actually the process of taking cells from the surface of the cervix and processing them and sending them to a pathologist to look at under the microscope. It is not the process of looking in the vagina. Everyone should have their organs looked at every year, even if you don't have a cervix, there's skin and tissue down there that needs to get looked at that's hard for us to see ourselves.

But with regards to cervical cancer screening, it is usually based on your age, so from 21 to 29 it's recommended that you get a pap test every three years. For ages 30 and up, depending on the type of pap test, if you get a regular pap test with no HPV screening, you would still do three years. If you get the HPV test in addition to that and it is negative, you can do screening every five years.

The U.S. Preventative Task Force recommends that we stop screening at age 65, but I always tell patients there's caveats to that. That means that not every person is the same, just because you're 65, we have to go through your whole history. So if you have had a history of severe dysplasia, which is what we call pre-cancer of the cervix or pre-cancerous changes of the cervix, you might not be a patient that we would stop screening at 65. If you have new partners later in life, or you may have newly been exposed to HPV, which is a very common sexually transmitted virus, you may not be a patient that we would stop screening at age 65. So it is important to ask your doctor if you are the right candidate, with

regards to how often you are getting your pap test.

Lauren Hixenbaugh: Okay. All right. Just wanted to kind of clarify that. And then the other part of that question, we will go back to which is, serving that underserved population, and kind of the recommendation there.

Dr. Galvan Turner:

Absolutely. So West Virginia does participate in a West Virginia Breast Cervical Cancer Screening Program. So there are providers across the state who work through that program that patients can apply to. It is an income-based program and it is an application that you'll have to fill out. But if you meet the criteria for the program, we can put you in touch with providers who can do your pap smears. Other places where you can look to have your pap smear done, would be the Department of Health, a Planned Parenthood, which there is one in West Virginia in Vienna. I know that there is a Health Right in Morgantown, and then I know that we have the ability to have patients call in and help find a provider who is in that program.

Lauren Hixenbaugh: Yeah, so folks can actually call our office, Cancer Prevention and Control, and the phone number is (304) 293-2370. You can just ask whoever answers the phone that day, you can just ask about the Breast and Cervical Cancer Screening Program and they will connect you with somebody, an expert who can help you get linked there. You can also visit the West Virginia Breast and Cervical Cancer Screening Program's website. It is hosted on www.wvdhhr.org/bccsp. So folks can find those resources at those two locations. Are there any additional questions that you get from patients that you feel like you want to cover?

Dr. Galvan Turner: I often get asked from patients ... The patients, as I said, who end up being better candidates for radiation, a big question that we will get is, "When am I going to have my surgery after my radiation?" And it is important for me to make sure that they understand that not every patient with cervix cancer is going to get surgery. Not everyone is going to be a candidate for a hysterectomy. And certainly, after you have gone through radiation, surgery becomes a much riskier procedure to do, and it is not often something that we do. Again, everyone's treatment plan is individualized. But it is important that they know that once they've been treated, their cancer has been treated, and even if the organ remains there, we don't have to take it out. It is too risky to take it out. It is better to leave it there. It has been treated, it doesn't have cancer anymore. So that's always something that we make sure to educate patients on.

A lot of questions that I get of, this is a hormone driven cancer, like some of the other cancers, such as ovarian and uterine cancer. This is not a hormone driven cancer and oftentimes, we try to preserve patients' ovaries, so that they still go through menopause. If they are haven't done so yet, they'll go through the change of life. They may not have the signs and symptoms of a period, but they'll go through the other hormonal changes. That's another big question that we get.

Patients often want to know what causes cervical cancer. And with cervical cancer, it's one of the only cancers where we know the causative agent. In about 90 to 95% of cases, the causative agent of cervical cancer is the HPV virus. And we do have a way to prevent cervical cancer, which is an amazing feat of science. There is the HPV vaccine, which is now available to persons, men and women, up to age 45; it's now been approved up to age 45. So when the vaccines first came out and were first promoted, patients

were told if they were older than 21 they shouldn't get it anymore; they weren't candidates. But now it is up to age 45, we can see a benefit for both men and women.

So I think it is a wonderful thing to promote the HPV vaccine. It is safe, it's been tested and it is a vaccine that will prevent cancer. It absolutely will prevent cancer and many other HPV related diseases, not just cancer. It is recommended that children who are in the 11 to 12 range get their HPV vaccine series, which is great, because instead of three shots, if you get it when you are 11 to 12, you get two. So that's another great way to kind of promote the vaccine in less shots. But you can still be a candidate for the two vaccines series up to age 14.

Lauren Hixenbaugh: That is great. That is wonderful. If listeners were to remember one tip from today, what would you want them to remember from our talk?

Dr. Galvan Turner: It is important to get your well checks, your wealth screenings. Even though you aren't feeling sick, that's how we want to keep you. We want to keep you healthy. It is important to go to a doctor to get seen. And even though it can sometimes be uncomfortable or embarrassing to get a pelvic exam, it is important. So make sure they include that with your well-check. We do not want you to wait until you are starting to feel symptoms or have concerns that something might be wrong. We want you to get there before anything gets wrong, so that we can keep you healthy.

Lauren Hixenbaugh: Yeah, that is a great thing to remember. I would even add that prevention in there.

Dr. Galvan Turner: Yes.

Lauren Hixenbaugh: The prevention and the early detection both, I think are big things that we talked about today.

Dr. Galvan Turner: And that's a big part of your wellness check, that's always a part of it. Screening and prevention is included in that as well. And that's another thing after cancer treatment that a patient can sometimes forget about. We develop a very close relationship with our cancer patients, and the focus for a lot of years becomes, treating the cancer, preventing it from coming back. Now it has not come back, and they are used to coming to see us on a regular basis, but they've forgotten to get their mammograms, or their colonoscopies, or to get their vaccines, because they're now 65. So that is another big part of survivorship, which is one of the reasons we're talking today. Because the cancer can become all consuming, and even when the cancer is gone, it's still at the forefront of your mind. But I have to remind patients that it is important to eat healthy, to get their flu shots, to get their mammograms, their bone density screenings, and their colonoscopies. All of those things are important too. Once you have beat cancer, we want to keep you healthy.

Lauren Hixenbaugh: Yeah. And get back to living your life.

Dr. Galvan Turner: Exactly.

Lauren Hixenbaugh: Yeah, absolutely. So we talked about some resources today, but I just wanted folks to remember that we do have the Living Beyond Cancer Facebook support group available. Like I said,

you can search that on Facebook at Living Beyond Cancer. And then we also have the Mountains of Hope website, the State Cancer Coalition, which is moh.wv.gov. And you can check out the WVU Cancer Institute's webpage, wvucancer.org.

Lauren Hixenbaugh: Thank you so much for being here with us today. So today on Living Beyond Cancer, we had Dr. Valerie Galvan Turner, and we hope that our listeners will continue to join us and thank you again for being here today.

Dr. Galvan Turner: Thanks for having me.