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Speaker 2:

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Kenny:

Hi, everyone. Welcome to our next episode of the Genetic Counselors and You podcast. As some of you may already know, September is Prostate Cancer Awareness Month. According to the American Cancer Society, other than skin cancer, prostate cancer is the most common cancer in American men. In fact, one in eight men will be diagnosed with prostate cancer and his lifetime.

Kenny:

What factors increased my risk for prostate cancer? Family history? What can I do? In this episode we invited Joy Larsen Haidle, a board certified genetic counselor, to share her thoughts. Joy is a leader in cancer genetic counseling, who has authored several practice guidelines and published articles on topics such as Lynch syndrome, a disease that increases one's risk for cancers, particularly of the colon and rectum. And juvenile polyposis, a disorder characterized by polyps in the gastrointestinal tract. She also was on this podcast two years ago.

Kenny:

A past president of National Society of Genetic Counselor, Joy is a genetic counselor at North Memorial Health Cancer Center in Robbinsdale, Minnesota. Welcome, Joy, and thank you for joining me today.

Joy Larsen Haidle:

Hi, Kenny. Thank you for having me join the podcast this afternoon.

Kenny:

Thanks for spending time with me to discuss this very important topic. I think the first question I would love to ask you to share with the audience is, do you mind sharing what your experience is in seeing patients related to prostate cancer?

Joy Larsen Haidle:

Sure. I'm a clinical cancer genetic counselor at a community hospital that's located in Minnesota. So I see patients who have prostate cancer, who are in the midst of making their treatment decisions, perhaps because they have metastatic disease. Men who have prostate cancer who have a family history of prostate cancer, or perhaps a combination of other cancers. Or I'll see patients who are healthy, that are wondering about their family history and whether or not they should be thinking about changing their surveillance or considering risk reduction based on their family tree.

Kenny:

I see. And can you share a little bit more about how common prostate cancer is and what percentage of that may be hereditary?

Joy Larsen Haidle:

Sure. I think, I appreciate you having this topic because the genetics of prostate cancer is very important to help inform men and their families about situations that they could consider testing. As you mentioned, in the general population roughly one in eight men will develop prostate cancer over a lifetime. And so that likelihood of developing prostate cancer can be modified based on family history or based on someone's race.

Joy Larsen Haidle:

For example, African American men have a higher chance of developing prostate cancer over a lifetime, it's in the range of about one in six. The age of onset might be younger and the disease may also be a bit more aggressive than men who develop prostate take cancer by chance.

Kenny:

Wow, I see. It sounds like this is definitely a complicated topic, and it's also common in men as well. And so can you share a little bit more about some common questions that patients may ask you related to prostate cancer?

Joy Larsen Haidle:

I think some of the most common questions that I get in clinic is, "With what my personal or my family history looks like, does it look like there is an inherited component? What are the costs that would go along with testing? What can the test tell me, what can't it tell me?" Probably more importantly is what would we do with that information.

Joy Larsen Haidle:

Other common questions deal with the how we do the testing, because it could be done either by a blood sample or saliva sample, is it equal in quality? Should they get their children tested? And I think a common misconception is, "Because I've already been diagnosed with cancer we shouldn't be testing myself. I really should be testing somebody else in the family instead." And realistically, we'd rather start with the person in family who's had the cancer to see if the test could even work and answer the question for that given person.

Kenny:

I see. Can you elaborate a little bit more about that, in terms of why testing an individual who has cancer first is important.

Joy Larsen Haidle:

Sure. If we think about cancers broadly, about five to 10% of cancers, to name the kind of cancer will have an inherited component that will go along with that. In a man, for example, who has metastatic prostate cancer, that chance could actually be closer to 12 to 18% chance that I might find something on a genetic test. When we think about testing, what we're doing is, there's not a one-size-fits-all test that works for all men with prostate cancer.

Joy Larsen Haidle:

And that's where working with a genetic counselor can be really helpful, because we'll walk through your family history and your personal history, looking for clues that there's something more than chance that led to that prostate cancer. And so we'll talk with you of about the kinds of tests that might be reasonable to consider based on the types of cancers that we're seeing in your family. And in doing that, what we're looking for is the chance that that test might provide a useful result for the person, as well as their family members.

Joy Larsen Haidle:

If I have a man who has metastatic prostate cancer, for example, that is someone who's called an informative testing candidate. That means that if I test this person their results are useful to themselves, as well as anyone else in the family that's related to them by blood. So it also is where the highest chance that we could find something. So if I test you and you happen to have an inherited risk factor, that's very valuable to you, for your own medical management decisions, but also the rest of the family.

Joy Larsen Haidle:

But if I test you and I cannot find anything, there's no mutations identified, what that's saying is that it doesn't mean there's not an inherited component, it just reduces the likelihood that testing other members of the family would add value. It may just add additional cost, but we may be in the same position just by doing a detailed family history and risk assessment instead.

Kenny:

I see. Thanks, Joy. And you mentioned cost as a common question as well. Can you share a little bit more about how affordable genetic testing is around this?

Joy Larsen Haidle:

Often it depends on the kind of test that someone is pursuing. At the major diagnostic laboratories, many of them will be the billing entity and they will bill the insurance companies and put the prior authorization in place. And if there is expected out-of-pocket expense, they would be in touch with that person to explain to them, under the rules of their own policy, "This is what we'd anticipate out-of-pocket."

Joy Larsen Haidle:

There are times that if there's an insurance policy that has a specific policy exclusion, or the person chooses not to utilize insurance, they'd rather pay out-of-pocket, that the cost of insurance could be switched to a cash pay option. And the cost of that can be variable from one laboratory to the other, but a common example, hovers right around 250 to $300.

Kenny:

I see, that's very helpful. Thanks, Joy. You mentioned genetic testing as something that may be important for one to consider. Can you share broadly more about what the standard screening tools are for prostate cancer?

Joy Larsen Haidle:

There's two components of your question. One is the actual screening tools, the other one is what do we look for in that family tree. If it's okay with you, I'd like to address the family tree part first-

Kenny:

Yes.

Joy Larsen Haidle:

... and then let's circle back to the screening. Because it's always easy when you look at a family tree and there are the same kind of cancer that's in the family. Meaning you have multiple people in the family that have prostate cancer, it's easy to spot that. But there can be other cancers that can be seen in the family tree also that might seem like they're completely unrelated or not connected in any way, but when a genetic counselor looks at that family history, we might be able to tie those together under one inherited risk factor.

Joy Larsen Haidle:

Other cancers that you might see in a family tree could include breast cancer, ovarian, or uterine, colon cancer and pancreatic cancer, in addition to the prostate cancers. Depending on the pattern of cancers that's in the family that might add information about what kind of screening or surveillance a specific person or their family members might benefit from.

Joy Larsen Haidle:

For example, traditionally screening for prostate cancer is twofold. It's a combination of doing a PSA and then a digital rectal exam. And so often what happens here is there's a movement in the general population right now away from screening for prostate cancer, because the thought process is that most men who are diagnosed with a prostate cancer, it might be more of a slower growing putzy type of prostate cancer and they would do fine if we just continued observation in.

Joy Larsen Haidle:

There are a group of men who will have a more aggressive type of prostate cancer. And what we're trying to figure out is how do you identify which men will be in which of those categories. When we know that there is an inherited risk that is responsible for the prostate cancer in a family, what's important here is that it's indicating that that in individual and the men in their family should actually go forward and pursue the prostate cancer screening. The ages of onset that we start might be younger. So men with some of these inherited mutations or risk factors may start their prostate screening around 40 instead of 50 in the general population. And how often they do the screening might be more frequently, such as an annual basis instead of every two to four years.

Joy Larsen Haidle:

When we're thinking about from a healthy population trying to screen, that can make a bit of a difference of, "Do I need to do it at all? How old should I be when I start? And how often do I need to do it?" And then because most of these genes have a job to do in more than one part of the body, we're also asking, "What else should I be doing to keep myself healthy? Do I need more frequent colon screening? Am I at increased risk for pancreatic cancer and would benefit from doing that kind of screening?" And for men and women in the family, is there an increased risk of breast cancer, and for the women in the family the additional question of, "Is there an increased risk of ovarian or uterine that we should either think about doing screening for, or perhaps even risk reduction?"

Kenny:

I see. It sounds like knowing this information may also benefit not just myself, but also the entire family as well, in terms of their potential risk for other cancers that may be associated with this syndrome, for example.

Joy Larsen Haidle:

That's exactly right. There are times that men who are diagnosed with a prostate cancer may also be able to add information to, for example, their daughters or their sisters about breast and ovarian cancer risk. And in addition to sons and brothers for prostate risk.

Kenny:

Thanks, Joy. How would one find a genetic counselor like yourself so that they could talk to a genetic counselor to learn more about their risk, if they're concerned based on their family history?

Joy Larsen Haidle:

I think the easiest option is findageneticcounselor.org. So on that website you have the ability to identify a genetic counselor that can see you either in person. Many genetic counselors, especially during COVID, have been able to offer telehealth, so there's consultations that are available by telephone or by Zoom. And that's offered an increased ability to access genetic counselors, especially for people who live in rural or traditionally underserved areas. And there's less time away from work when you're able to do an appointment telehealth, versus having to drive in in person.

Joy Larsen Haidle:

In those cases, when we're trying to do testing, it's just as easy to do a blood sample versus a saliva sample to offer that remote consultation, both of which are equally accurate in testing. If you happen to be fortunate and you're in a town that has a genetic counselor, we're happy to see you in person. If your doctor's office does not have a genetic counselor, certainly know that that findageneticcounselor.org is a great tool to help you find a qualified provider.

Kenny:

Thanks, Joy, and will definitely include this in the podcast information as well so our audience can click on the link if they're interested to schedule an appointment with a genetic counselor as well.

Kenny:

And I think one final question I have is, we definitely brought up genetic testing broadly during our discussion today. Can you share a little bit more information about when in may not be appropriate or at times when it definitely would be appropriate to consider? And maybe more nuances, in terms of you brought up it be tested through blood or saliva or ... Can you share a little bit more information about that?

Joy Larsen Haidle:

Perhaps I'm a little bit biased. I work with a lot of different people and for the most part, I think if a person has questions or they're concerned about the risk for themselves or for their family members, a genetic counselor's always going to be happy to meet with them to answer those questions and talk through those risks.

Joy Larsen Haidle:

There are times that hen we, as a counselor, take that family history and we'd spend the time drawing out, "How many people are in your family, what kinds of cancers they've had. How old were they at the time that they were diagnosed? What kinds of surgeries or treatments people had." Really what we're looking for, it's like putting together a puzzle and each of those nuggets of information is helpful in determining the level of risk that could be assigned to another family member on whether or not they would benefit from testing. And there are that, as part of that risk assessment or that conversation with a genetic counselor, that we will pick up risk factors that other providers that do not specialize in genetics, may not have been as familiar with. So it's worthwhile.

Joy Larsen Haidle:

For the most part, if someone is just worried, I tend to reference it as the worried well, where there's no family history, large number of people in the family that mostly lived well into their elderly years, no known cancer diagnoses that were identified. The yield on doing genetic testing would likely be relatively low. So for the cost involved with doing genetic testing, that person might not have the same amount of benefit. However, sometimes the conversation with a counselor can still be valuable to offer that level of reassurance that they're looking for.

Kenny:

Thanks, Joy. And thanks again for your time today to speak with us. Do you mind sharing some key takeaways that may be helpful for the audience to know?

Joy Larsen Haidle:

Sure. Some of the key takeaways are genetic counselors are a part of your medical team, that we can be an expert resource to help answer your questions about genetic testing and your family history. And speaking of family history, when you're thinking about risk, take a look at all of the kinds of cancers that might be present. That family history, if there's breast, ovary, uterine, pancreas, colon, or prostate, those are types of cancers that will make us think about the possibility for inherited risk.

Joy Larsen Haidle:

Gene testing is become more commonplace and it can be used to influence treatment decisions for individuals with cancer, particularly men with metastatic prostate cancer. It can be used with their oncologist to help determine what medications they might benefit from taking. So across the board, all men with metastatic prostate cancer are candidates to get gene testing. Men who have a Gleason seven, prostate cancer or higher, or men who have prostate cancer and a family history, are all candidates that may benefit from considering genetic testing or meeting with the genetic counselor.

Kenny:

Thanks, Joy. This is very helpful to me, I'm sure this will be helpful to many of our audiences as well. Thank you again for your time today.

Joy Larsen Haidle:

Thank you. I appreciate the opportunity to chat with you.

Speaker 4:

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