The vast majority of sarcomas happen for reasons we just don't understand, and it is a continued area of interest. Because the more we know about what causes a cancer, the better we can be at treating it.

Sarcoma is the general term for a broad group of cancers that begin in the bones and in the soft tissue. With more than 70 types of sarcomas, the correct diagnosis is key for the best treatment and management of these cancers.

We know that diagnosing sarcoma can be very challenging, and there have been studies that have shown that over 40% of diagnoses are changed when they're reviewed by a medical oncologist.
Dr. Halena Gazelka 00:45
Welcome, everyone to Mayo Clinic Q&A. I'm Dr. Halena. Gazelka. Sarcoma is a general term for a broad group of cancers that begin in the bones and in the softer connective tissues in the body. Sarcomas that begin in the bones are called bone cancer, and sarcoma that forms in the tissues, including muscle, fat, blood vessels, nerves, tendons, and the lining of joints is called soft tissue sarcoma. Here to discuss the various sarcomas and their management with us is Dr. Brittany Siontis, medical oncologist at Mayo Clinic. Thanks for being here today. Brittany,

Dr. Brittany Siontis 01:21
Thanks so much for having me.

Dr. Halena Gazelka 01:22
Well, I love to learn something new every day, and sarcomas are not something that I know very much about. And I know that it is a Sarcoma Awareness Month, and so what a good time for us to learn a little something.

Dr. Brittany Siontis 01:35
Absolutely.

Dr. Halena Gazelka 01:36
Tell me a little bit about what is a sarcoma, and how common are they?

Dr. Brittany Siontis 01:40
Well, you're not alone in feeling like you don't know much about sarcomas. These are rare cancers, and in adults, sarcomas comprise less than 1% of new cancers diagnosed every year. So, most people never hear about sarcoma. And we're so grateful to have Sarcoma Awareness Month, to try and bring more education to the population about this rare tumor. Sarcomas, as you mentioned, can happen in what we call the connective tissues of the body, or the things that hold us together. So, we see them arise from bones, muscle cells, fat cells, they can happen anywhere in the body, and we can see them in patients of all ages. There are over 100 different types of sarcoma. So, it's actually a very diverse
group of cancers that fall under this umbrella of sarcoma.

Dr. Halena Gazelka 02:31
Is it more common to see sarcomas that arise in the bone or in other connective tissues?

Dr. Brittany Siontis 02:36
Great question. It depends on the age of the patient. So, in pediatric patients, the bone sarcomas are much more common than the soft tissue sarcomas. The exact opposite is true in the adult population, where about 80% of the sarcomas we see in adults are the soft tissue type.

Dr. Halena Gazelka 02:53
Do we know what causes sarcomas?

Dr. Brittany Siontis 02:55
We don't. The vast majority of sarcomas happen for reasons we just don't understand. And it is a continued area of interest, because the more we know about what causes a cancer, the better we can be at treating it.

Dr. Halena Gazelka 03:08
Oh, sure. That makes sense. If we don't know what causes it, are there certain risk factors that would portend a higher risk of developing a sarcoma?

Dr. Brittany Siontis 03:17
There are a few that we know about, we know that there are certain cancer genetic syndromes, which can predispose patients to certain types of sarcoma. In addition to other types of cancers, one of those being Li–Fraumeni syndrome. Although, that being said, most of our sarcoma patients do not have a genetic cancer syndrome. We also know that exposure to prior radiation therapy can increase the risk of certain sarcomas. So, sometimes, if patients have had radiation to treat a different type of cancer, breast cancer, for example, they could potentially be at risk of developing a sarcoma many years down the line.
Dr. Halena Gazelka  03:55
Interesting. I thought you were going to say smoking, it seems like smoking is a risk for almost every badness.

Dr. Brittany Siontis  04:01
Not sarcoma, as it turns out.

Dr. Halena Gazelka  04:04
That's very interesting, because I'm always saying, as I'm interviewing people, be it heart disease or cancers, but almost everyone says, don't smoke. So, we'll say that anyway.

Dr. Brittany Siontis  04:14
We'll say don't smoke for many other reasons.

Dr. Halena Gazelka  04:16
That's right. Many other cancers.

Dr. Brittany Siontis  04:18
Yes.

Dr. Halena Gazelka  04:19
Brittany, what are the signs and symptoms of sarcoma that might bring someone to medical attention?

Dr. Brittany Siontis  04:25
Definitely, if someone notices a new lump, or bump really anywhere on their body, particularly if it seems to be growing over time. Those are things we definitely want to hear about. We tend to say anything that's bigger than about the size of a golf ball is something that should be evaluated by your doctor, especially if it's growing. Most folks tend to say, well gosh if it's not painful, then I probably don't need to worry about it. And in fact, that's not the case. Certainly, if something is causing pain, another great reason to go see your physician, but not all sarcomas cause pain. So, it's really a new lump or bump
Dr. Halena Gazelka 05:05
That's interesting. I would have guessed pain as well. And a golf ball seems pretty large, I'd probably be running to my doctor before it was a golf ball size,

Dr. Brittany Siontis 05:13
It's always good to seek care sooner, especially if you notice that it's getting bigger over time.

Dr. Halena Gazelka 05:19
Sure. And how do you diagnose a sarcoma if there's a suspicion?

Dr. Brittany Siontis 05:23
It's usually a combination of imaging and biopsy. So, depending on where in the body the lump is located, we would have either an ultrasound, but more likely an MRI or a CT scan to get a good look at that area. And then if there's suspicion that it could represent a cancer, or if the appearance on the imaging is just what we call indeterminant, then we would typically have our interventional radiology colleagues perform a biopsy. So, our pathologists can get a good look at that under the microscope and help us make a diagnosis.

Dr. Halena Gazelka 05:57
And I would imagine that this varies because you said there are 100 types of sarcoma, so the treatment must vary as well. But in general, what are the treatment options for sarcoma?

Dr. Brittany Siontis 06:07
Great question. In general, when we're dealing with what we call a localized sarcoma, or a sarcoma that's confined to one part of the body, the typical treatment would be a combination of radiation and surgery to get rid of that tumor. The role of chemotherapy is somewhat controversial in soft tissue sarcomas, though there are specific instances where we might consider giving chemotherapy. In bone sarcomas, even when they're localized, there is a very clear role for chemotherapy. So, some combination of chemotherapy,
radiation and surgery. When we're dealing with a metastatic sarcoma, or a sarcoma which has spread beyond the place where it started in the body, we are typically looking at using chemotherapy to try and keep the cancer under control.

Dr. Halena Gazelka 06:56
Interesting. And are there innovative approaches to cancer and ongoing research, I imagine for sarcomas, as well?

Dr. Brittany Siontis 07:03
Absolutely. We, here at Mayo Clinic, have a number of clinical trial opportunities for patients who have a diagnosis of sarcoma. Again, because there are so many different types of sarcoma, the eligibility for those trials varies. But we are always looking at new chemotherapy drugs or combinations of chemotherapy drugs. We're looking at new ways to combine drug therapy with radiation for those localized sarcomas. And though these are rare cancers, I will say the community of oncologists, surgeons and radiation oncologists who treat these cancers and are trying to improve the outcomes of these cancers continues to grow. So, there's a lot of research in this area.

Dr. Halena Gazelka 07:44
Brittany, I had one question about radiation just because you mentioned that we do proton beam radiation at Mayo Clinic. Are sarcomas an area where proton beam radiation might be used or not.

Dr. Brittany Siontis 07:56
Absolutely, we have really wonderful radiation oncology colleagues who specialize in the management of sarcoma. And we do often utilize proton beam therapy, which we know can have fewer side-effects and less radiation dose to surrounding tissues. So, it's certainly something we consider here.

Dr. Halena Gazelka 08:14
Brittany, how can patients make sure that they are receiving the very best care that they can get for their sarcoma when it is diagnosed?
When it comes to sarcomas, because these are rare cancers, we really stress to patients the importance of obtaining their care at a high-volume sarcoma center. And we certainly know that those centers are limited around the United States. But when we’re dealing with something that is so rare, it’s really important to have a team of folks who are comfortable with these cancers, familiar with how these cancers behave, and know the data to help make the best treatment plan for each patient. So, I always stress to patients, if they’re able to seek an opinion at a large volume sarcoma center such as ours, that’s really very important. Even when it comes down to the diagnosis, we know that diagnosing sarcoma can be very challenging. And there have been studies that have shown that over 40% of diagnoses are changed when they’re reviewed by a sarcoma pathologist. So, that specialty care really starts at the time of diagnosis.

That is a really significant variation.

Yes.

Brittany, when people come in for a second opinion, or because they want to have an opinion about their sarcoma here, do they necessarily receive all of their care here from us? Or do they sometimes go home to receive some of their care? How does it work?

It really depends, and I’ll say it depends on the patient’s wishes and it depends on their ultimate treatment plan. Oftentimes, we will recommend any sort of local therapy like radiation or surgery to be done at Mayo Clinic. Again, those are very technical procedures that you really want done in the hands of someone who does this all the time. When it comes to chemotherapy, certainly, if it’s a clinical trial, that would be done here with us at Mayo Clinic. If it’s more "standard chemotherapy", there are absolutely opportunities for patients to receive that chemotherapy with their local medical oncologists, under our guidance and collaboration.
We’ve talked so much during COVID about how virtual visits and the use of telemedicine has expanded. And I think that’s just amazing that we’ve been able to extend our reach to individuals who couldn’t necessarily travel here during COVID. And it’s a convenience actually, now that people are traveling a bit more as well. Do we offer virtual visits to individuals who might want to get an opinion from Mayo Clinic about their sarcoma?

We do. And I will say it’s really transformed our practice. And it has allowed us to be able to maintain relationships with our patients who live far away and can’t travel very easily. And it allows us the ability to review their records, provide them that specialty opinion, for folks that aren’t necessarily able to travel here. So yes, we are absolutely offering virtual second opinions, I have found it to be incredibly rewarding. And I hope the same is true for my patients.

I have to agree with you, Brittany, even in the Pain Clinic, you know, we’ll see someone who’s come in for something else and is referred to the Pain Clinic, and so do their initial consultation. But it is so nice to be able to see them virtually and follow-up with them. It used to just be a phone call, or they’d have to wait till they came back the next year to see me or whenever they were returning. So, I think it’s amazing.

It’s been wonderful.

Tell us a little bit more about clinical research for sarcomas. What sort of things are being studied?

So, certainly, as I mentioned, we’re always looking at new chemotherapy drugs, whether they’re brand-new drugs that are just being developed and wondering whether they could be effective in sarcomas, or are looking to use drugs that we already know about in a new way in sarcomas, perhaps a new combination of drugs that’s not been used before.
Outside of drug therapy, as I mentioned, we’re looking at lots of research in the lab. My particular interest is in biomarkers. So, I’m very interested in looking at patient’s blood and looking at the tumors themselves. Are there things that we can glean from the blood to help us determine if a patient is responding to chemotherapy? Or to monitor them for recurrence of their cancer? Are there things we can learn about the tumor itself that can help us develop new and more effective drugs? There are folks that are looking at cancer virus therapy, and how can we use those to augment the immune system to attack these cancers better? So, I certainly have a biased opinion. But I think it is a very interesting and ripe area for research, we have so much to learn. And we continue to work at it every day.

Dr. Halena Gazelka 12:56
And I can see why you’d need to be at a large sarcoma center to be able to do that research, because you said these are kind of rare cancers.

Dr. Brittany Siontis 13:05
Absolutely, it is much more challenging to do big clinical trials in sarcoma, unlike breast cancer, or prostate cancer, where there are 1000s of patients diagnosed every year, we are much more limited. And again, when we’re really dealing with 100 different diagnoses under the same umbrella, they all behave in slightly different ways. So, we need to make sure we’re not just always lumping them all together, and really making those nuanced decisions based on the specific type of sarcoma a patient may have.

Dr. Halena Gazelka 13:36
Is there a way that interested individuals, perhaps our listeners or our future patients could find out about clinical trials that Mayo Clinic may have ongoing for sarcomas?

Dr. Brittany Siontis 13:47
Absolutely. The Mayo Clinic website does have a list of active clinical trials. And each of those clinical trials will briefly describe what the study is about as well as contact information. And so, if a patient is reading and they think they might have a question or be interested in a particular trial, they can absolutely reach out through the website.

Dr. Halena Gazelka 14:06
Brittany, tell me a little bit about cancer survivorship, what are the survival rates for sarcomas?
Dr. Brittany Siontis  14:15
Again, it's always I think, in cancer in general, that's a really challenging question to answer. But again, when we're dealing with such a complex cancer with so many different subtypes it can be variable. If we look at data specifically for soft tissue sarcomas in adults, there was the SEER database, which is a database that houses long-term follow up and outcomes data for patients in the United States with cancer. And looking at the outcomes for soft tissue sarcoma at five years, about 80% of patients who have a localized soft tissue sarcoma, again, meaning it's confined to one part of the body, are alive at five years. If we look at patients with metastatic sarcoma, so cancer which has spread to other parts of the body, only about 15% of patients are alive at five years. Again, we know that each sarcoma behaves slightly differently. So those numbers are different for different types of sarcoma. But that's sort of a generalization.

Dr. Halena Gazelka  15:20
Brittany, we talked about virtual visits and how we've been able to extend care. And we've also become very conscious at Mayo Clinic that we want to be able to provide care to all comers, that we are very concerned about there not being disparities in healthcare delivery. Are there disparities related to the management of sarcomas or even survivorship that you could share with us?

Dr. Brittany Siontis  15:46
I think the biggest issue with sarcoma really is access to experienced providers. Again, this is a rare cancer, there are far fewer of us that specialize in sarcoma than specialize and other more common cancers. And I think that real disparity comes in when folks are unable to get at least an opinion from a high-volume center, which is familiar with these diseases. I think virtual medicine has absolutely expanded our reach and helped to minimize that disparity.

Dr. Halena Gazelka  16:21
Yeah, that's exciting. We look forward to more of that as time goes on.

Dr. Brittany Siontis  16:24
Absolutely.
Dr. Halena Gazelka  16:25
Anything else you’d like to share with our listeners today, Brittany?

Dr. Brittany Siontis  16:28
I would just like to thank you for having me today. Sarcoma is just a huge passion of mine, and we're always looking to increase awareness. So, thank you very much for hosting.

Dr. Halena Gazelka  16:38
Well, we are delighted that there are those who are passionate about sarcomas, Brittany.

Dr. Brittany Siontis  16:42
Thank you.

Dr. Halena Gazelka  16:43
Thank you for being here today, Dr. Brittany Siontis, medical oncologist at Mayo Clinic and discussing management of sarcomas with us. I hope that you learned something. I know that I did. And we wish each of you a wonderful day.

Narrator  16:56
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