Mayo Clinic Q & A - Proton beam for sarcoma – Dr. Safia Ahme...

Thu, 5/12 4:17PM • 25:52

SUMMARY KEYWORDS

patients, radiation, sarcoma, proton beam therapy, treatment, tumor, proton therapy, bone, sarcomas, treat, tattoos, radiation oncologist, normal tissues, high doses, rays, pelvis, radiation therapy, symptoms, mayo clinic, cancer

SPEAKERS

Dr. Halena Gazelka, Narrator, Dr. Safia Ahmed

Narrator 00:01
Coming up on Mayo Clinic Q&A, a bone sarcoma is a type of cancer that can be treated with surgery, chemotherapy, or proton beam therapy that precisely targets the cancer.

Dr. Safia Ahmed 00:12
When we talk about proton therapy, we talk about the benefits of proton therapy and how it's different from standard x-ray treatment. One major benefit of proton therapy for bone sarcomas is that we're able to give a very high dose of radiation to these tumors while protecting the normal tissues.

Narrator 00:30
Prior to proton beam therapy, CT and MRI imaging may be required to determine the best course of action to target and treat the sarcoma.

Dr. Safia Ahmed 00:39
The reason for these multiple scans is it gives me the best picture of the tumor and what exactly I need to treat, as well as where the normal tissues are and how best I can protect them. It's a process where we are very meticulous because we want to come up with the best radiation plan that is safe and is effective for our patients.

Dr. Halena Gazelka 00:39
Welcome, everyone to Mayo Clinic Q&A. I'm your host, Dr. Halena Gazelka. Sarcoma is a term for a group of cancers that begin in the bones and in the soft or connective tissues. Sarcoma that begins in the bones is often called bone cancer. Bone cancer is a rare disease, it accounts for only 0.2% of all cancers. Treatment for sarcoma can include surgery, chemotherapy, and radiation. One big advancement in the treatment of bone cancers has been the use of proton beam therapy. This is a more precise type of radiation therapy than traditional x-ray radiation. Joining us today to discuss

Transcribed by https://otter.ai

proton beam therapy for sarcoma is Mayo Clinic radiation oncologist, Dr. Safia Ahmed. Welcome to the program, Safia.

Dr. Safia Ahmed 01:01
Thank you Halena, for the introduction. It's such a pleasure to be here.

Dr. Halena Gazelka 01:53
First of all, let's just start with understanding sarcoma. Where does sarcoma of the bone or bone cancer typically appear?

Dr. Safia Ahmed 02:01
Yes, that's a great way to start. Many of our patients ask the same questions. As you pointed out, sarcomas are so rare, and most of our patients are actually referred to sarcoma centers for treatments, and that's where we kind of start our conversations. When we think of sarcomas of the bone, a few main sarcomas come to mind. That includes Ewing's sarcoma, osteosarcoma, chordoma, and chondrosarcoma. There are different subtypes of bone sarcomas, and to be honest with you, these subtypes of sarcomas can literally happen in any bone in the body. But common sites include the pelvis, the spine, and the skull base for most of these tumors. With symptoms for these bone sarcomas, it honestly depends on the site where the tumor is. Oftentimes patients can have pain. So, for instance, if you've got a bone sarcoma involving the pelvis, the pelvis bone actually contains a lot of nerves as well. And those nerves help give us functions for our legs. They help us control our bladder, they help us with our bowel movements and sexual function. So, sometimes patients will have pain if they're having a pelvic bone sarcoma, they may notice differences in how they're going to the bathroom and whether they can control their bladder and bowel movements. And they might notice differences with how they're walking and their strength with their legs, as well as sexual function. The same type of thing can happen in the spine or the skull base. The spine keeps our spinal cord. So, again, a big nerve bundle that helps with function for our body. So, if you've got a bone sarcoma involving the spinal cord near your arms, you might notice changes with your arm function, strength and pain. And then in the skull base, you might notice changes with vision, headaches, and so forth. And when I refer to the skull base, I'm talking about the bones that sit right behind our eyes and nasal cavity and mouth.

Dr. Halena Gazelka 02:43
Interesting. So, how would someone know if they had a sarcoma? What are the symptoms? And how do you diagnose this? That all make sense. It sounds like some of the symptoms that you could have for many different disorders as well. So, I guess that's why it's important to present to your provider when you're not sure.

Dr. Safia Ahmed 04:16
Exactly, exactly.

Dr. Halena Gazelka 04:18
Safia, tell me how you explain proton beam therapy to your patients.

Dr. Safia Ahmed 04:23

Transcribed by https://otter.ai

Yes, that is a difficult topic to discuss with patients. I'll just take a step back first and talk about why we would use radiation therapy for bone sarcomas. As you pointed out, oftentimes we may think about chemotherapy, we think about surgery, and think about radiation. So, when patients come to Mayo, which is a renowned sarcoma specialty center, they are seen by the entire team, and the team has a discussion about which treatments would be best for our patients. And if it's felt that surgery by itself would not be successful, and radiation would be a better modality by itself, or radiation will be added to surgery, then patients would come see a radiation oncologist at Mayo who specializes in sarcoma. At that point, we meet with the patient, and we talk about what radiation is. And we explain that radiation is given to the tumor to kill the cancer cells. And when we talk about proton therapy, we talk about the benefits of proton therapy and how it's different from standard x-ray treatment. One major benefit of proton therapy for bone sarcomas is that we are able to give a very high dose of radiation to these tumors. When we treat these tumors with radiation, they need much higher doses of radiation than say a sarcoma that arises purely in the muscle, what we call a soft tissue sarcoma. And these high doses of radiation often exceed what the normal tissues around the area can tolerate. So, proton therapy allows us to give this high dose of radiation while protecting the normal tissues. And I have a picture to show the audience.

Dr. Halena Gazelka 04:56
Wonderful.

Dr. Safia Ahmed 04:58
If that's okay with you. I'm not an artist, so I apologize for this. Please let me know if it's coming clearly, I hope you are able to see this. So, I've got a representative image here of the pelvis. So, this is what we call a cut through picture through the body. And I've drawn the pelvic bone here. And then generally, the pelvic contents that sit in front of the bone, and the blue is supposed to represent the tumor. So, normal tissues that we have to be mindful of when we're giving radiation include the bowel, the bladder, the rectum, and then the nerves that sit around the pelvic bone and in the pelvic bones. For women, we also think about the uterus and ovaries, especially if they're young women, and would like to have reproduction as an option down the road. And then depending on how low we go into the pelvis we also have to factor in male genitalia. So, with x-rays, these are signified by the arrows here. The x-rays would enter the body, they enter the body in multiple different directions, they successfully treat the tumor, and then they pass through the rest of the body and exit the body. When you're giving very high doses of radiation, you will see that first of all, it will be difficult to treat this tumor because x-rays continue beyond the target. And we would expose the normal tissue to potentially high doses of radiation, which could be harmful. And then we expose lots of the other normal tissue in the area to radiation as well. We don't like this, especially for children and young adults, because this leads to potentially permanent damage down the road. And even for some adults too when we're using high doses of radiation that could lead to permanent damage. In comparison, down here is proton, and the same pelvic contents here, the pelvic bone and the tumor in blue. The way protons work is where again, coming in with multiple different angles with the radiation, they treat the tumor, and they virtually stop just a few millimeters beyond the tumor. And so, the high doses of radiation stop very close to the tumor. So, we're able to give that high dose of radiation while protecting the normal tissue. And then the radiation doesn't travel through the rest of the body. So, you're also getting rid of the low-dose radiation

Transcribed by https://otter.ai

that the normal tissues would see. So, that's how I describe proton therapy. It allows us to treat the tumor without treating the normal tissue around it.

Dr. Halena Gazelka 08:24
Well, that's a wonderful explanation, Safia. It's very easy for me to understand when you explain it so clearly. How do you decide if a bone cancer is appropriate for proton beam or if you will use traditional radiation?

Dr. Safia Ahmed 08:41
Multiple factors go into that decision. One, the type of bone sarcoma, specifically whether the bone sarcoma would benefit from a high dose of radiation, and also what normal tissue is nearby. If you have the nerves, the spinal cord, the nerves for the eye if you're up in the skull base, the brainstem, things like that. We also factor in the patient age, especially for children and young adults. Anytime we give radiation, unfortunately there's a risk of a secondary cancer developing in the area that we treat, and proton therapy would help minimize that. And then also discussion with the rest of the sarcoma team, including medical oncology and surgery. If we're pairing radiation with surgery, we work with the surgeons to figure out how best to minimize the risk of new complications that could happen with surgery, especially if we are giving radiation beforehand. So, we're factoring in multiple different aspects of the patient's tumor, the patient's themselves, their age specifically, and then what the overall treatment plan is.

Dr. Halena Gazelka 09:45
You talked with your diagram a little bit about the risks of traditional radiation therapy in the adjacent tissues, or the tissues that are traversed can be damaged. Are there risks to proton beam therapy, and what are they?

Dr. Safia Ahmed 10:01
Unfortunately, there are risks anytime we give radiation. When we meet with patients, we talk about the side-effects that a patient would experience while they're getting radiation. So, this means that the side-effects would start during the treatment course and then would continue once they start for the rest of the treatment course, even for a few weeks afterwards. When I say treatment course, some of these tumors can take up to six, seven weeks of daily treatment, Monday through Friday. So, we're talking about a pretty long haul for some patients. And with the acute side-effects, again it depends on where the tumor is. But common side-effects include fatigue, the skin changes, you saw on the diagram that radiation has to pass through the skin to get to the tumor. So, oftentimes, patients have skin redness, and sometimes feeling of the skin like a sunburn. And then the tumor itself can swell from the radiation because it's getting irritated by the treatment. And when there's swelling, if the tumor is putting pressure on nerves, some of the symptoms patients are experiencing like pain, changes to how they're walking, how their pelvic organs are functioning, could temporarily get worse too. And when that settles down then we talk about long-term side-effects. And again, that also depends on what area we're treating, I'll just focus on the pelvis because that's what we were talking about. In the pelvis, we think about potentially permanent damage to the nerves, if they're nearby the tumor. We try to keep that risk low, under 5%. We quantify that risk for each patient We can also have fracture of the bone because these high doses can damage the integrity of the bone, and the tumor to some degree might do that, too. So,

Transcribed by https://otter.ai

it's a combined effect. And then all potentially risk of damage to bowel, bladder rectum if it's nearby, and then the risk of another cancer developing, just a few.

Dr. Halena Gazelka 11:52
Safia, how can patients best prepare if they're going to undergo proton beam therapy?

Dr. Safia Ahmed 11:58
I think the best thing our sarcoma patients can do once they're diagnosed with a sarcoma, one is to come to a sarcoma specialty center. And when you're scheduled with the radiation oncologist to please come with questions you have. We understand that these are very rare tumors. And oftentimes, patients may feel like I don't know if I'm doing the right thing. I have no idea what all these radiation words mean, and so forth, so come with questions. And our team in particular will tell you how best to prepare for your radiation planning. That's a specific appointment we do to actually design the radiation plan custom to each patient, and then what to specifically do in preparation for each treatment that you receive every day. So, we'll give you that guidance. And sometimes what we may tell you to do maybe to come with pain medication on board, because you may be in so much pain that it's hard for you to lay flat for treatment, or to come with a full bladder, perhaps sometimes. The bladder fullness can affect how much bowel is in the radiation field. So, that may help us design a better radiation plan. My point is it's custom for each patient. Just come with questions you have because we know radiation may sound scary, and our patients are going through so much already. And the team will tell them specifically how to prepare.

Dr. Halena Gazelka 13:19
For my patients, I often give them the analogy that when I take my car to the mechanic, I may know the name of some of the parts, maybe even a little bit about what they do. But I really know nothing about car engines. And so, I rely on their expertise. So, I may ask dumb questions or questions that I feel dumb asking, but there is no dumb question. So, I always encourage, and I know you do too, our patients to come with questions of things they wonder about. And no question is foolish.

Dr. Safia Ahmed 13:51
Absolutely true. I agree with your analogy 100%.

Dr. Halena Gazelka 13:55
So, what should patients expect to experience during proton beam therapy?

Dr. Safia Ahmed 14:02
So, the first appointment is to meet with the radiation oncologists that would be treating you and the rest of the team. At that point patients would hear our recommendation for whether we recommend radiation or not, what type of radiation we recommend, and how long the radiation will be, as well as the expected side-effects and how to prepare. After that consultation, and if the patient's agreeable, then we move forward to what we call a simulation. It's basically a dress rehearsal of how the radiation will go. That could be one appointment that lasts for maybe an hour or two, perhaps a whole day of appointments. The main thing with that appointment is that we are getting the patient in the treatment position we want them to be in for daily treatments. It's important they not move during treatment,

Transcribed by https://otter.ai

because the radiation is so focused and precise. So, we make those custom immobilization devices first, and then we obtain a CT scan while the patient is in those devices. We might add contrast to the CT scan. We might also get an MRI in that position as well. The reason for these multiple scans is it gives me the best picture of the tumor, and what exactly I need to treat, as well as where the normal tissues are and how best I can protect them. And then it can take up to a week and a half for me and the team to actually design the radiation plan. I sit down next and actually draw out where the tumor is on the scans, I draw out what area needs to be treated, I draw out all the normal tissues and how best to protect them. And then the team and I work together to actually design how the radiation enters the body, where the radiation stops in relationship to the tumor, and so forth. So, it's a back-and-forth process. It's a process where we are very meticulous about because we want to come up with the best radiation plan that safe and is effective for patients. And then once that process is done, and the patient is ready to start, they come in daily for their treatments Monday through Friday. The radiation therapists are the ones who actually set up the patient in the room with their immobilization devices, they confirm that the patient is in the correct spot, that everything looks very good before they turn the treatment machine on to treat them and oversee the whole process. Sometimes they ask for feedback, if they're struggling with a particular positioning issue, and so forth. Everything's very safe. And then while patients are going through treatment, they meet with me at least once a week to see how things are going and to manage any side-effects that come up. And of course, if patients are experiencing lots of side-effects that need extra support, we're happy to meet with them more than once a week The team is always around to make the patients feel as comfortable as possible.

Dr. Halena Gazelka 16:46
Now, one thing that surprised me about radiation therapy was tattooing. Tell me about that. Do most patients receive tattoos to help you with localization?

Dr. Safia Ahmed 16:55
Yes, most patients do. And that's, you know, a great question. The tattoo is actually very small. Most people when they think about tattoos, they think about, you know, the rather, perhaps something of a picture that's sentimental for them or whatnot. But the tattoo is actually the size of like a very, very small mole or birthmark, and it's blue. And it's placed in the area where the tumor is. The purpose is to help with positioning. So, when the patient is placed on the treatment table in their immobilization device by the therapist, we're all about precision. So, one of the first steps they take is to use the tattoos to line up the area as well as the rest of the patient correctly. And they use lasers that are in the room to help guide that alignment. So, you've got lasers focusing in on the tattoos to kind of be a starting point, and then once everything looks good based on the tattoos, then we move on to taking x-rays to confirm that the internal bones and whatnot are in the right spot. And sometimes we might do a quick CT scan as well to confirm beyond the x-rays that everything is in the right spot before we turn the treatment machine on. So, it's a multi-step process to ensure the position is good. The tattoos are given at the time of simulation.

Dr. Halena Gazelka 18:14
What is the recovery. Oh, sorry, Safia, I didn't mean to interrupt.

Dr. Safia Ahmed 18:18

Transcribed by https://otter.ai

Oh no sorry. They are permanent, unfortunately.

Dr. Halena Gazelka 18:23
Tell us what recovery is like after receiving proton beam therapy for a sarcoma.

Dr. Safia Ahmed 18:30
Again, it depends on what area of the body we're treating and what side-effects the patient might be experiencing. But we tell patients to kind of give themselves, you know, a good two to four weeks to recover from treatments, I always tell my patients the day after radiation treatment is not the time to perhaps start training for a marathon or to do anything excessively difficult on your body. Oftentimes patients are experiencing fatigue, and the fatigue that they experience is the body's way of telling them, you need to slow down so I can use energy to heal from the treatment that I'm getting. And so, we tell patients to take it slow. The skin reaction may last for, you know, about two weeks after we're done. And then it'll slowly start to recover. And perhaps about a month afterwards, patients feel like they have more normal skin. The swelling also comes down over the course of several weeks. So, they start to notice an improvement with symptoms that could be related to the swelling. And then if they're having pain, we hope that the pain improves as the tumor continues to die. Radiation can have an effect on the tumor for several weeks after we're done. So, the first kind of look we take at the tumor with scans after treatment is usually about three months afterwards to give enough time for the swelling to go down so we have a clearer picture of what's going on. So, yes it could take several weeks to recover from the radiation, and most patients say it's about a month afterwards that they're starting to feel a little bit more like normal.

Dr. Halena Gazelka 20:05
What else do you want patients to know about proton beam therapy?

Dr. Safia Ahmed 20:10
I think what surprises patients the most when they come to see us, and we talk about the treatment logistics is how long it can take. And the fact that we actually treat til midnight. So, yes the treatments themselves, so we have four treatment rooms, and what we call one proton beam that's split between the four treatment rooms, and one patient is actively receiving the beam is what we call it. And then the three patients in the other rooms are getting set up. So, they're going through that process of using tattoos to use to get set up and x-rays to confirm. And then patients may have to wait until it's their turn to receive the beam. So, because of the staggered effect of receiving treatment, it can take up to an hour to receive the treatment. So, it's very important we tell our patients this when we're doing the simulation, let us know if you're comfortable on the treatment table. If you're not comfortable you're gonna wiggle over that one hour, and then we're gonna have to start over with repositioning. That's why having good pain control is important. Make sure you tell us what's comfortable, what's not. Because there are ways we can make the treatment position more comfortable for you. And then like I said, because things are staggered, and we have a very busy proton center, we usually start treating around seven o'clock in the morning, sometimes earlier, and going till about midnight. So, patients are surprised that they might have an 11 o'clock treatment time. That's not ideal. I would definitely want to be sleeping at 11 o'clock at night. But sometimes we have to do that to accommodate everyone.

Transcribed by https://otter.ai

Dr. Halena Gazelka 21:42
Understood. Is most proton beam therapy done with curative intent, or is it also used palliatively, in other words to decrease symptoms like traditional radiation therapy might be?

Dr. Safia Ahmed 21:56
I would say most cases with proton therapy are for curative intents. But I know many cases are also used for palliative intent. I see a lot of styles. I specialize in treating all sarcomas in all parts of the body, and I have had palliative sarcoma cases where unfortunately patients have metastatic disease, but may have a tumor, for instance, in their lung that's involving the entire side of the lung that's causing significant symptoms for the patients. They can't breathe, they can't talk, they can't swallow anything. So, their nutritional status is going down. Even though it's palliative, I still favor sometimes proton therapy in cases like that, because I don't want to give a radiation dose to the opposite lung that doesn't have the tumor. Giving high doses of radiation to the lung can cause other issues. And so, to protect the other lung I have sometimes used proton therapy for palliative cases. So, it just depends on the scenario and where your physician thinks there may be a benefit.

Dr. Halena Gazelka 22:58
So, once an individual has undergone proton beam therapy and maybe what is called no evidence of disease, or they have no residual cancer left, what is follow-up like for them? And is there concern about cancer recurrence?

Dr. Safia Ahmed 23:12
Unfortunately, there's always concern about cancer recurrence. We've made so much progress with all of our treatments and our survival outcomes and our efficacy with our treatments have improved and continue to improve. But there's no 100% guarantee. We discuss that with patients and what the likelihood of effectiveness would be especially if they have proton. And with surveillance, like I said, the first scan is generally done about three months after the radiation treatments to give time for things to settle down so we have a clear picture. And then we work with the medical oncology surgical teams to decide how best to follow them. Oftentimes, the first two years patients are receiving scans of the area that was treated, as well as the chest because the sarcoma has a tendency, sarcomas in general have a tendency to spread to lungs. And they're receiving these images about once every three to four months for the first two years. And then after that, after the two-year mark up to year five, oftentimes it's every six months, and then after that it could be on an annual basis or so forth. Oftentimes medical oncology discusses with the patient. We also have lots of patients who travel here for proton from all across the country, even across the world. Sometimes it's impossible for them to make those trips frequently. So, we can work with the patient to perhaps have scans done at home, and then meet with us virtually to review the scans that were done at home. Or we can have patients come up once a year, especially in the summer, not in the winter, and then have the rest of their surveillance at home. So, it really depends on what works best for the patient.

Dr. Halena Gazelka 24:52
Thank you so much Safia, for being here today. This has been incredibly informative.

Dr. Safia Ahmed 24:57

Transcribed by https://otter.ai

Thank you for having me. It's been a pleasure to speak with you.

Dr. Halena Gazelka 25:01
Our thanks to Dr. Safia Ahmed, radiation oncologist at Mayo Clinic, for being here today to talk to us about proton beam therapy for sarcoma. I hope that you learned something. I know that I did. And we wish each of you a wonderful day.

Narrator 25:17
Mayo Clinic Q&A is a production of the Mayo Clinic News Network and is available wherever you get and subscribe to your favorite podcasts. To see a list of all Mayo Clinic podcasts, visit newsnetwork.mayoclinic.org. Then click on podcasts. Thanks for listening and be well. We hope you'll offer a review of this and other episodes when the option is available. Comments and questions can also be sent to mayoclinicnewsnetwork@mayo.edu.

Transcribed by https://otter.ai