

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'The Value of a Second Opinion'

Description:

One of the most important reasons to seek a second opinion is to protect yourself from misdiagnosis. Researchers have found that the rates of misdiagnosis and mistreatment are higher than you might suspect. Join Alicia and Lizette from The Leukemia & Lymphoma Society (LLS), as they speak with Dr. Pallawi Torka, *Assistant Professor of Oncology* and *Co-Program Director* of the Hematology/Oncology Fellowship Program, at Roswell Park Comprehensive Cancer in Buffalo, NY. Dr. Torka speaks about the importance of a second opinion, red flags that indicate when a second opinion may be needed and how to approach this sometimes uncomfortable topic with your healthcare team.

Transcript:

Alicia: Welcome to *The Bloodline with LLS*. I'm Alicia.

Lizette: And I'm Lizette. Thank you so much for joining us on this episode.

Alicia: Today we will be joined again by Dr. Pallawi Torka, who is an Assistant Professor of Oncology and Co-Program Director over at Roswell Park Comprehensive Cancer Center in Buffalo, New York. For those who would like to listen to our other episode that we recorded with Dr. Torka, titled, "A Bright Future for Hodgkin Lymphoma," you can find that episode within the episode listing, both in your app or at theBloodline.org. Welcome back, Dr. Torka.

Dr. Pallawi Torka: Thank you, Alicia.

Alicia: Now, Dr. Torka, on Roswell Park's website, it states that between 11 to 18% of second opinions that physicians provide at Roswell for patients from outside of Roswell Park involve a change of diagnosis, which is very startling when you think about what that could potentially mean for a patient. A different diagnosis may come with a host of different treatment options, potentially different side effects, and, of course, a difference in overall outcome.

So on this episode, we want to discuss the benefit of a second opinion, how to eliminate the hesitancy or some would say awkwardness that can exist when attempting to address this topic with their healthcare team.

Although some would say that the phrase or term second opinion is self-explanatory, how would you define second opinion and why is it important?

Dr. Torka: So, as you mentioned, it is pretty self-explanatory what a second opinion is. However, there can be different flavors of a second opinion. So, for example, a second opinion is basically when you want to go seek another opinion for your condition. It could happen when a loved one or a family member mentions that they know a doctor they trust and suggest that you just seek out the other doctor to make sure that you're on the right path. It may be even encouraged by your treating doctor when they don't have any more options available for the condition, and they would like a patient to seek an opinion at a higher level of care, a center which has clinical trials and such. And sometimes when someone is not comfortable with what's going on and just wants to ensure that everything is going in the right direction, they might go for a second opinion.

In conditions such as cancer where the treatment and the outcomes are so important and life-changing, it is always good to seek a second opinion, even if everything is by the book and everything is going well. And most oncologists I know would encourage such a practice.

Alicia: And that's such a great point to mention that it's encouraged and that you can seek out a second opinion at any stage of a diagnosis or any stage of the conversation with the healthcare team because I was reading a lot of articles and some patients waited until they felt uncomfortable, but they had already started treatment. Some people think that you should only seek a second opinion when they feel like something is unclear. But even if you have the best conversation with a doctor, having multiple eyes or lenses on something could be very helpful. To your point, right?

Dr. Torka: Absolutely. Also, because the practice of oncology is changing very rapidly. So, something which was standard of care yesterday may not be the standard of care today. And it is difficult for every oncologist to be up to date with all the standard practices and best practices. In which case, it may be very beneficial to go to an institution where they have specialists for example, I do lymphoma and that's all I do. So, I have much more time at my disposal to keep up to date with the latest and greatest in lymphoma therapy than a general oncologist who has to take care of patients with all sorts of cancers.

Alicia: Right.

Lizette: Dr. Torka, I know that in some cultures it's harder for people to bring up a second opinion with their physician. Have you experienced that in, in your practice?

Dr. Torka: Many times. So, you know, as a physician, what hurts me is when a patient of mine goes for a second opinion and does not tell me; and then later I hear about it. I would like to know so that I can even call the doctor and say, "Listen, my patient is coming to you. Here's my cell phone. If during the visit you have any questions or something in my notes doesn't make sense, please give me a call so that you can give the best opinion."

Lizette: Wow.

Dr. Torka: It is always good to let your doctor know that you're going for a second opinion. Doctors might take it differently. We are human beings; and sometimes it hurts, when you think that my patient doesn't trust me and is going for a second opinion, but we get over it very quickly because at the heart of every physician is to do what's best for the patient. And even if they know that medically the treatment decisions are going to be the same, sometimes it helps people emotionally and it helps them cope when they have sought two, three opinions and they know that they're absolutely doing the right thing. And it also builds their trust in their own doctor because if they go to a bigger center and the specialist is saying the same thing, then they feel like, "Wow, my doctor really knows what they're doing." And then they don't go again. They start trusting the doctor more. So I don't see any downside of a second opinion as such.

Lizette: Right, and at the same time, getting a second opinion doesn't actually mean that you're going to switch doctors. It's just getting a second opinion. I mean you could switch doctors, but it's not necessary. Most people stay with their original doctor.

Dr. Torka: I would say so, at least in my practice.

Alicia: Now as a doctor, when a patient comes into your exam room or to your office and they're sitting and they're speaking with you, and the issue of a second opinion does come up, for patients and caregivers who are listening, how would you suggest that they delicately approach that topic in a way that is comfortable for, for both parties? Now, to your point earlier, of course, we're all different people and we receive information differently, and may interpret that and react to them differently, but in

your case and in your past experience with patients and caregivers, how would you suggest that a patient might bring this topic up and not feel so intimidated by it?

Dr. Torka: That is a very good question, and it's difficult to answer. I would suggest just bringing it up, asking the doctor, "What do you think about a second opinion? Do you think it's worthwhile going for a second opinion anywhere?" and see what the doctor says. If the doctor says this is a very rare condition and I encourage a second opinion, then you know that the doctor supports it.

If the doctor says that this is standard of care, if you go anywhere else you're going to hear the same news, then you could follow it up with asking, "Well, would you mind if I just went for a second opinion, just for my own piece of mind. I know you're doing the right thing, but I would just feel better if someone else told me the same thing because I need multiple endorsements of this decision."

And then the third is the more difficult scenario where your suggestion may not be taken in a positive manner. In which case then you have to decide how would you best approach it without severing ties with your treating physician? But that happens very rarely in my experience.

Alicia: And that's such great advice. I remember speaking with another physician who said that another way of approaching this might also be speaking to the doctor or to the current doctor and saying, "Is there anybody in that field that you respect that may have a different opinion or may have a different outlook on, on my diagnosis and my scans or whatever it is, so it appears as if the conversation is one in which the person hears what the doctor is saying and may also respect the viewpoint of another physician, and that way it kind of looks like a team effort as opposed to "I'm going somewhere else because I don't trust you or, your diagnosis."

Dr. Torka: I think that's a very good idea. That's a great way of saying it.

Alicia: Can a patient or caregiver ask for a second opinion while in treatment?

Dr. Torka: Absolutely. So, you know, some people are planners. They like to know what if. So, there are many people who go while in treatment, first of all, just to make sure that the treatment that they're getting is standard of care. And second, in case this current treatment doesn't work out, what are their options so that they can plan their lives, plan their finances; and if they need to move in the future for a clinical trial, they are mentally prepared to do so.

So there are many people who go online, and if there are any particular treatments that they would be interested in the future, actually go to those centers and establish themselves there as patients just in case.

Lizette: And I know you said that some patients are planners, and they like to plan ahead. I know that you, you spoke that, you do deal with lymphoma; and with the indolent types of lymphoma, a lot of times the treatment plan can be observation or watch and wait. Do you find that a lot of patients ask for a second opinion or go for a second opinion when they are given that type of treatment plan, watch and wait, just because some patients might not be comfortable knowing that they have cancer and that they're not getting some type of active medication for their cancer?

Dr. Torka: I think you hit the point there. Definitely, we see a lot of second opinions there. People come exactly for that reason, and I, I feel like if I was ever in that situation, I would probably do the same too. Just make sure someone else also endorses that wait and watch is a good idea, even though I have cancer. And that does form a majority of second opinions in my practice.

Lizette: I know that it, it's been difficult with me talking to patients that have had a watch and wait protocol that were not comfortable with it just because they weren't comfortable with the whole notion.

Dr. Torka: Watch and wait is difficult for patients because there is that anxiety that while we are waiting, the cancer may grow, but once a conversation is had and once the patient is made part of the decision-making process that, well, at this point treatment is more dangerous and more harmful than waiting, then they are pretty comfortable with the decision. And I think in those instances a second opinion really matters.

Alicia: Doctor, you mentioned something that is also I think a very important point to stress, and it's the shared decision-making aspect of treatment and this cancer journey. I think that, to your point, when it comes to a second opinion, and when it comes to speaking to multiple doctors and having different conversations or hearing different feedback on maybe a particular scan or test or just having a different conversation, I think also allows for there to be confidence for a patient or caregiver to know that they were part, and intimately a part of their diagnosis because like Lizette was saying earlier, if someone gets a diagnosis and they just kind of go with he knows best as opposed to he knows a lot, but there's also other doctors who may also have a different opinion about this, it helps them to feel that confidence in knowing that

they're doing their part advocating for their own health since their part of the entire decision-making.

Dr. Torka: Absolutely, absolutely.

Alicia: Doctor, has there ever been an example of maybe for yourself or that you heard of in which a patient came to you and it ended up being a different diagnosis which then, of course, changed the outcome of their care?

Dr. Torka: It has happened several times. So as, as I've mentioned before, I take care of patients with lymphoma, and there are over 90 to 100 different types of lymphoma per the latest WHO [World Health Organization] classification. So when a patient comes for a second opinion to my institute, and I know that in other institutes that's the policy too, they get not only an opinion from me, but their slides are also brought over and read by a hematopathologist rather than a general pathologist. And in many instances, the diagnosis is changed under our pathologist's hands, and that has a bearing on treatment.

For example, where the treatment decisions are changed most is differences between low-grade and high-grade lymphoma. There is no distinct boundary between the two and it's a continuum. So sometimes, for example, what happens almost once a month is that the patient's biopsy showed a low-grade lymphoma, but when you look at the PET scan, really the PET scan was suggestive of something more aggressive.

Now you can't go biopsy every single spot to prove that a patient has aggressive lymphoma, so in those instances we treat what can be really harmful as the aggressive lymphoma, in which case the treatment can be different, and the outcomes are very different. So, I think it's worthwhile where the clinical pathologic radiographic correlation is not optimal, to go for a second opinion and make sure that everything fits.

Alicia: Well said, thank you. And what are some red flags that indicate that someone may need a second opinion?

Dr. Torka: So, I would say the situation then when someone should think of a second opinion is any time, they don't feel comfortable with what's going on. And if they don't feel heard, if they feel like they're bringing up issues and complaints which are not being addressed. If they have a rare condition which maybe their doctor sees once a year, then it might be a good idea to seek out an expert who sees it more often. and even if you think of it, you know it's worthwhile exploring it. If there is somebody

nearby who is more trusted or who has the expertise and it's not much of a time and effort investment, then it's a good idea to go for a second opinion. You know, it helps you become your own advocate and push for the best care.

Alicia: What are your thoughts on someone going outside of their primary physician medical center for a second opinion versus going to another physician within their own center for a second opinion?

Dr. Torka: So different institutes have policies on that. For example, in my institute, if I know that I'm seeing a condition for the first time or the case is a little complicated, I would just go to my boss who has much more experience than me and who may have seen many patients in the same scenario and ask what they would do in the situation.

Many places have tumor boards where all such cases are discussed, and which saves the patient time and effort to actually have to go for a second opinion. In many institutes, though they do not have this in which case, if you needed an opinion, you would actually have to formally see the other doctor.

In many other institutes though, also, there is a rule that you cannot go for a second opinion with a doctor in the same practice. So it really depends on what the local practices are. But, it's definitely worth asking and then, you know, the answer is what you get, what happens there.

Lizette: Being that a lot of patients are from rural areas and they're not able to travel to a larger cancer center usually in a more urban area, is there any possibility for those larger cancer centers to provide a second opinion just through technology, through the phone or through just sending the information?

Dr. Torka: That's a very good point. Our country is huge and not everyone can travel. So, there is something called a 'virtual consult' which is offered by many centers where the charts are faxed over and the doctor can review the charts and give an opinion.

There is a little caveat to a virtual consult is no matter how good the charting is, to see someone physically there and to see what they look like and to hear them out is different and meaningful. However, in many cases, doing a virtual consult can be very, very helpful. You know, in case someone is looking for a clinical trial, then the virtual consult may be enough.

The other thing that can be done is the treating physician can pick up the phone and call an expert across the country or even across the world to get a second opinion. And I know most people are very happy to help. And it can be achieved that way without somebody really needing to travel for a second opinion.

Lizette: That's great. Does the patient have to initiate that, or do you find that most physicians initiate that themselves?

Dr. Torka: For when patient cannot travel, I think most physicians initiate that because it's hard for a patient to find out who offers those services. So, I feel that it is mostly the physicians who do that. In fact, even in some big hospital systems, what they do is that where they have rural practices which are affiliated to a university, they have it built in their system where the rural physicians can do virtual consults with the mothership and find out what's going on there. So, yeah, and I think it's going to grow because now with FaceTime and, you know, Google Talk and all these technologies, it's really as if the patient is sitting in front of you.

Lizette: Wow!

Alicia: Yeah, I got injured the other day and like there was something where my back was hurting, but I wasn't sure if I should actually go anywhere. And I called my insurance company to ask actually a different question and I mentioned that I was going to go look into my back and get that checked out. And they said, "Would you like to hold because we have a nurse that can actually FaceTime you and talk to you to see if it's something that you should actually go for further care." And I was, I was blown away 'cause I was thinking to myself, I called the insurance company not, my primary doctor, and it was so accessible. It's pushing the needle forward in a great way so that patients and caregivers can feel like they can really get what they need at any point.

Dr. Torka: Absolutely.

Alicia: So, doctor, just going back, I was reading this article that I thought was very interesting, and it was a patient who had gone out to lunch with this medical oncologist and he asked how often he treated a patient for cancer without a second opinion. And the medical oncologist replied, and he said that he had never in his career treated a cancer patient without a second opinion. And he insisted that the patient do that in order for him to move forward because his rationale was, one, cancer is a very serious disease and if it's not diagnosed properly the first time, there's often no second chance.

And he often said, two, "The doctor is human and could make mistakes." His third rationale was that someone else could see something that one doctor doesn't see. And finally, he said, "Someone else can know something that one doctor doesn't know," which is what you said earlier. And, you know, the, the patient who's thinking about what the doctor said and his conclusion was that any doctor treating a cancer patient without encouraging a second opinion in his words said, "Was not practicing medicine but trying to play God," which I found very interesting when I was reading this article because he was basically saying that it's a team effort and to encourage more and more doctors to kind of join on board or more eyes to see something that is so life changing was definitely necessary for each and every patient.

Dr. Torka: I think I agree, and I disagree too a little bit, to a, to a little extent. I agree that second opinion should be encouraged, but I also feel that a doctor should know their strengths and weaknesses. You know, going for a second opinion is an investment on part of the patient. It takes time. They have to take time off work. They, in many instances have to travel. There's a copay. So if something is really standard practice and the doctor does that ten times a day, then they should have built up a confidence to be able to know what's right and what's not. And they should also know where things are not lining up or where they're out of their depth and encourage a second opinion.

But to make a blanket statement and say that, oh, every case needs a second opinion is a stretch. I, I don't think it's practical. You know, it's something like you should always think about it and say, "Well, yes, this, this case needs a second opinion," and, "Well, no, I think I got it." That kind of a scenario basically.

Alicia: Yeah, that makes sense. That makes sense. And to your point, there's a lot of factors that go into the process of a second opinion. So definitely.

What advice do you have for patients and caregivers listening today?

Dr. Torka: I would like to say that, you know, it's good to go for a second opinion and in most cases, both the doctors will agree on what needs to be done. But there would be instances where when you go for the second opinion, the doctor may tell you a different treatment plan. And your first doctor, your main doctor does not agree. And then the patient's in a quandary because now there's this, disagreement and you don't know which doctor to trust.

In that instances, either a third opinion might help or you kind of have to just sit down with the doctor and ask why the two doctors are disagreeing and then you can be the

tie breaker about. Depending on what your values and what your goals of your care are, you have to be your own advocate. But it's not like either doctor is wrong, it's just that for example, if someone has breast cancer, one doctor might recommend mastectomy, meaning remove the whole breast, whereas some other doctor may recommend, lumpectomy, take a small piece out and follow it up with radiation, which could both be options but then you have to sit down and tease it out to see which makes more sense to you. And then you have to be comfortable with whatever decision you make. And that can be tricky sometimes.

Alicia: We couldn't agree more.

Lizette: Yeah.

Alicia: Dr. Torka, thank you so much for not only what you do for your patients but for speaking to us about second opinions and the importance of a patient feeling comfortable with their decisions that they make with their healthcare team. We definitely appreciate your time with us today.

Dr. Torka: You're most welcome. Love doing what I do.

Lizette: Thank you.