



Living with a Stoma – Understanding and Managing Parastomal Hernias

Guest Speaker:

Ziho Lee, MD (Northwestern Memorial Hospital)

Patient Advocate:
Darell Nakagawa

Patricia Rios:

And we're grateful for the years of schooling you've dedicated to be able to provide the service to our patient population, Dr. Lee. Darrell, I have a question for you related to the hernia. When you first became aware of it, did you know that it was a hernia? Did you know what it looked like? How did you first become aware of that and what tips do you have for others who are not sure and are considering whether to get that evaluated?

Darrell Nakagawa:

My hernia developed, started developing probably around the six-month post-cystectomy, and I just noted a little additional bump around the stoma. And I think I did ask my urologist because that was a time of more frequent visits, and he did sort of confirm that yes, there was a slight hernia, and we did sort of say we could hold off addressing it because we'd want to see if it gets any worse. And the protrusion of around the stoma did get larger over time. So the picture or the video, or the picture of the hernia that Dr. Lee showed was pretty much similar to what my hernia looked like. And Dr. Lee, that picture looked pretty even. Are there hernias that are more tilted or strangely formed?

Dr. Ziho Lee:

Yeah, I mean, I think that's a great point. I think the ones that we showed, I do agree with you, they do kind of look anatomically symmetric. We do I do see some odd shape hernia. Sometimes it could be a combined hernia with the incision where the cystectomy was performed. And so yes, like you can see some pretty nasty hernias. Fortunately, those are the minority of the hernias that we see.

Darrell Nakagawa:

Great.

Patricia Rios:

And related to delay, I know Darrell, you waited around seven, eight years to have the surgery. Dr. Lee, are there any, sort of, I don't know, complications or things that patients should be aware of if they postpone the hernia surgery? Does it affect their outcomes?

Dr. Ziho Lee:

Well, so most patients have this chronically and most patients wait for there to be an issue just because of the complex nature of the surgery. I will say with the hernia, especially if there's intestine in there, there's always a risk that can twist and get stuck and swell up, and that really is an emergency. And so if anyone's having intermittent pain in that area, I think getting prompt evaluation is important.

Patricia Rios:

Thank you. So another question that has come up is around patients who are exploring their diversion options. And a patient may say that the parastomal hernias is something that worries them as they're trying to decide whether to go for an ileal conduit or let's say a neobladder. Do you have any thoughts on this?

Dr. Ziho Lee:

Yeah, I mean, I think that's a great question. And it's really that is something that it really has to be individualized for the patient because it's trade-offs. I think there's risks and benefits with every type of decision. With an ileal conduit, I typically say it's the most time tested, simplest urinary diversion. You're in and you're out. Complications from it are pretty ... A lot more people can manage the complications of them and you're taking a smaller piece of bowel ... And for example, I've done ileal conduit on very young children who've had it 30 years ago and it's time for a new one and I don't have a problem with taking another piece of bowel because only a small piece was taken to make it.

With the neobladder, obviously I think it sounds amazing like you just get a new bladder. Complications from that can be pretty significant. Some patients don't like having mucus in their urine, but again, it's trade-offs. I think complications-wise, there's more recent data showing that the complications can be similar. But for me, it's really kind of a trade-off on what the patient wants and what they really value. Because again, it's kind of their lives. I mean, you know your life best and my job is just to tell you about the options and for you to make an informed decision.

And so I think with neobladders, if you have an issue with that, there's many less physicians willing to take that on. There could be sometimes issues with nighttime bedwetting, there's you can have some incontinence, there's ... There are risk and benefits to everything. And so I think really you got to talk with your urologist in detail and ask questions. And you don't have

to ask them all at once. I always say, "If you have more, make a list, send it to me on MyChart and we'll figure it out. And talk with your family or your friend or someone and bounce ideas off of them." And so I think it really has to be individualized.

Patricia Rios:

And I'll add to say that another resource that we have available is our survivor to survivor program where we match peers, volunteers with someone who has gone through a similar program, and Darrell can speak more about that. But we find that it is helpful as patients are trying to decide which diversion to choose that talking to someone who has one of the diversions, it becomes helpful. Darrell, do you have any comments?

Darrell Nakagawa:

Not really. I guess one question I keep seeing in the chat or question is, can there be hernias as an effect from all of the other diversions? So if someone has a neobladder or an Indiana pouch, can they get a hernia as well and can it be fixed robotically?

Dr. Ziho Lee:

Yes. So for example, I just recently did a patient who had an Indiana pouch. In those patients, so an Indiana pouch is essentially you're taking a piece of colon and you're making a reservoir or a container and you have a piece of intestine that can go through either the belly button or through your belly. And the patient every four to six hours will take a catheter and catheterize themselves to empty the urine. You can have hernias from that. I just did a case of that. In that situation, I do not like to use my mesh suture technique. What I do is I will actually close that fascia with the mesh suture and I'll place the stoma site at a different location, so I'll just move it.

Patricia Rios:

Okay. Thanks, Darrell, for bringing that up. Yes. And Dr. Lee, there's a question here from one of our patients. Regarding belly fat question, I've been told that I have a small parastomal hernia, but my urologist didn't seem worried about it or offer any ways to manage it. Any comments or suggestions for patients who are experiencing small hernias?

Dr. Ziho Lee:

Yeah, I mean, I think it's ... Obviously I'm not there at time of evaluation or what was said or what was done. In my experience, what I can say is if the hernia is asymptomatic, meaning that patients have no symptoms from it, it's small, they're not bothered by it, I typically recommend not operating on it. And it's because for me, sometimes less is more. And you really don't ... Every operation I do, no matter how good someone is, it's an operation. There's always risks. With not doing surgery, there's no surgical complications if you don't do surgery. And so if they're not having symptoms, I typically don't recommend treatment.

Again, as urologists in training, we all know what a parastomal hernia is, but in my training, I actually don't even remember if I even repaired one parastomal hernia and we know it's

common and usually because we would just send it to the plastic surgeons or to a general surgeon or someone else to fix. And so I think for me, if you're bothered by it, I think I would speak up and just make sure they're addressed. If someone does not have the expertise to address it, maybe asking to see someone else, a plastic surgeon or someone who's willing to see that or has more experience with that, I think that's what I would recommend.

Patricia Rios:

Thank you. And do you see these hernias more prevalent in older adults? Do you think the patient's age affects the recurrence of these hernias?

Dr. Ziho Lee:

Yeah, I certainly think with age, less muscle mass, the tissues get just, they're not as tight. I do think that older patients have high risk of hernias.

Patricia Rios:

And there's a question from one of our listeners around the evaluation of the hernias. Can hernias be evaluated with ultrasound? Does the CT have to have some sort of contrast or can it be evaluated without contrast? There's a question about can the mesh travel postoperative?

Dr. Ziho Lee:

Yeah, so I mean, those are great questions as well. The mesh, always you can have complications with mesh. And that's why I like my suture technique because you're using such a small amount and the only part that's actually visible in the body is the knot. And then each throw, which if it's tight, you're not going to really see much mesh. And so that's why I like that compared to putting a sheet of mesh, which I've had cases where I had to take that out and it could be quite difficult. What was the first part of that question? Sorry, I lost my train of thought there.

Patricia Rios:

No, it was about ultrasound using that for evaluation.

Dr. Ziho Lee:

I typically like a CT. I think it's much easier to see. I don't use any contrast. Usually if there is contrast, it's fine, but a quick non-contrast low dose CT is good enough for me and it shows everything that I need to see. And I think when patients see that, it's a very much easier to process.

Patricia Rios:

Okay. And there are quite a few questions around exercise. Again, if there is any exercise programs you recommend, or I know we talked about avoiding, not so much the avoiding, but

more about the weight loss. And can you speak about BMI? Because there's a question about what would be the ideal BMI for individuals?

Dr. Ziho Lee:

Yeah, I mean, it's hard because everyone has a different BMI and it's a lot of times things that you can't control like genetics and things of that nature. As a surgeon, I love seeing low BMIs, low 20s. I maybe get one of those every three, four months. A lot of the patients that I get referred are the higher BMIs where there's a lot higher risk for these hernias. I don't think there's an ideal BMI. What I recommend is just general health. A lot of times if you have bladder cancer, you got to get the cancer treated. I would not wait for surgery. Do your best, but that's why it's important just every day being intentional, trying to be healthy, trying to do some exercise a couple times a week, maybe 20, 30 minutes, it's very important. But just because you have a high BMI doesn't mean you're destined for complications. I've done cystectomies on BMI as high as 65, I think. So it's a wide range, and for me, it's like the situation is a situation and you just got to do your best. And that's how I approach these things.

Patricia Rios:

Two last questions before we close. This one is more around, again, identifying the hernias. This person wants to know if a bulge or a bump, does that necessarily mean it's a parastomal hernia or could it be something else?

Dr. Ziho Lee:

Not always a parastomal hernia. Sometimes initially at the early onset of surgery, just the way that the skin comes together, sometimes you can have a slight little outpouching that typically goes away with time. Usually though, if it's a bulge around the area, it's usually a stoma. Those are pretty easy to evaluate. I think it's worth an evaluation.

Patricia Rios:

Okay. And do you see bleeding by any chance? Is that rare?

Dr. Ziho Lee:

Typically not. You mean bleeding from the stoma?

Patricia Rios:

Stoma, around the stoma?

Dr. Ziho Lee:

Typically not, sometimes patients with really bad liver disease or cirrhosis, you could see some really bad bleeding. Typically, you shouldn't really be having that much bleeding from the stoma itself.

Patricia Rios:

Okay. All right. Well, thank you so much for staying a few minutes extra to be able to go through the questions. I know we didn't go through all of them. There were so many good questions submitted in advance and also in the chat. I wanted to give the two of you an opportunity to really provide the take-home message. What would you like our listeners to take home or remember after this presentation? And we'll start with Darrell and then we'll close out with Dr. Lee.

Darrell Nakagawa:

I'm really thankful that I did have the opportunity to get my parastomal hernia fixed. Living with it with minimal pain was also acceptable, but it's a personal choice of what's going to work for you and what is going to provide the easiest life for you.

Patricia Rios:

Thank you, Darrell. Dr. Lee?

Dr. Ziho Lee:

I think my biggest takeaway is, again, I agree with Darrell, just to piggyback, it's very personal. I think most of the hernias, it's not going to cause a life-threatening bowel incarceration, but I think having education and having a talk and an honest discussion with someone who has expertise in this area, I would strongly recommend. Some patients, it's the right answer, but again, for others, it may not be. And so I think it's really a personal decision and everyone's different. And I think that's very cool that in this day and age, a lot of our medicine is going towards more individualized care because not everyone is the same and everyone has different goals and values. And having the option to do something doesn't mean you have to do that something, and then it may be right for you and it may not be right for you. And I think the best way to know is talk to someone, talk to a medical professional, and it doesn't hurt. And so I think that would be my big takeaway.

Patricia Rios:

And thank you for emphasizing the importance of patients being able to express what's important to them. And so I think it's important for patients to be able to express that with their providers and with loved ones as they're considering many options, whether it is parastomal repair or other treatments.

So with that, I want to really thank the two of you for a phenomenal presentation. Thank you so much for your time, and we hope to have you back for a different webinar at a later time this year.

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