

Defining Your Goals—Making Shared Decisions in Surgical Bladder Cancer Treatment

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Part 4 of 4

Patricia Rios:

Dr. Chan, just want to thank you for a very comprehensive presentation. I really loved your example about a Honda and Mercedes, and I think that helped to really understand the difference. I also appreciated that you talked and stressed the importance of talking to a patient who has had one of these diversions, and I just wanted to take a moment to share that at BCAN, we have a program, a peer-to-peer program called Survivor to Survivor, and we'll put the link in the chat, where we are able to pair patients that are looking to have a cystectomy with another patient so they can really understand what life is with one of those radical cystectomies. So thank you for mentioning that.

I want to begin with a few questions that we have as it relates to the different diversions. Out of the three that you mentioned, which one would you say is the one that's most commonly done and least commonly done?

Dr. Kevin Chan:

Yeah, interestingly, 97, sorry, 93% of patients in the United States that get radical cystectomy get the external bag, the ileal conduit. So it's probably the most common. I think that's a product of a couple things, but probably it's the simplest operation. So if you don't do a lot of these operations, don't do a lot of neobladders or neo pouches, you generally steer away from them. So I'd say that probably is the reason it's so common.

What's interesting is the neobladder has been around since 1982. So it's been, I mean, almost 50 years we've had it, and we've made very, very slight inroads. At City of Hope, I'd say about 50% of our patients get ileal conduits and 50% get other things. There are some institutions where even more than that, where they really push neobladders even harder than us. I say we press pretty hard. We really try to avoid an external bag if at all possible.

It is technically a little harder. Like surgery, if you just don't do it a lot, you may just... In certain people's hands, obviously it's probably better to do a conduit. If that's all they do, then that's the right thing to have. I think in a lot of major cities, I think there are people that do all three options, and if that's something that's important to you, then I would try to explore that option.

Patricia Rios:

Great. Thank you for explaining that. You talked about the pros and cons or rather, who will be the ideal candidate for a particular cystectomy? This question just came in from Lisa in that let's say you start with an Indiana pouch. It could be a neobladder. The idea is that you started with a Mercedes and now you want to switch to a conduit in your mid 80s because of many reasons. Can you explain what would be some of the reasons and what do you do if things change?

Dr. Kevin Chan:

So it's interesting. Kathy and I have been doing this for 20 years now. Now we're getting those patients that are getting older and having some memory issues, but you've lived with it for 20 years fine, and now you're getting to that point in your life where it's become dangerous.

I think sadly, that's a very important point that Lisa brings up. At 65, yes, Indiana pouch makes the most sense. In your mid 80s, you would love to convert it to a conduit. Honestly, as we've unfortunately learned is when your memory goes, your health isn't great either. So to convert that, that's still a major operation.

It's actually easier to convert a conduit to an Indiana pouch than it is to convert the Indiana pouch to a conduit because I actually have to just remove the entire Indiana pouch and start from scratch to create the ileal conduit. I feel that that's a really big operation to put somebody in their mid 80s through.

So in general, and this is a question that comes up with my trainees as well, it's like, well, everybody's going to get to this point, should we be doing Indiana pouches? It's one of those things where it is 20 years, 15 years of enjoying your life. I don't know that you can avoid something just because something might happen 15 years from now or 20 years from now. That's why I do think when you're in your 70s, it really does

make sense to say, hey, does this make sense? How important is it for you not to have an external bag? I think that's a great question. It's a hard answer.

Usually when patients get older and need to be cared for and have an Indiana pouch and maybe their memory is not working, what we simply do is leave a catheter in their Indiana pouch and it'll go to a drainage bag. That's usually the simplest than going through a big operation. The problem with that is it actually still needs to be irrigated because the pouch makes mucus. So there's still a little bit of maintenance, even if you just wanted to leave a catheter in the pouch, probably needs to be flushed or can get clogged with mucus.

So I'd say when you get older into that timeframe and the memory starts to go, it's like there's a lot of things that are not ideal. I think it definitely more for the caretaker. I don't think there's an easy answer because it's a big operation to put someone through at 85 to just convert the pouch.

I will say in that same vein though, there are many people that might get an ileal conduit and they're 65 and they're like, you know what? I really don't want to have this bag for the rest of my life. We see this with colorectal patients and cervical cancer patients where it was a little unexpected, so they get a conduit, but we can convert that to an Indiana pouch. Relatively, it's not as big of surgery as a radical cystectomy.

So I think that's also a reasonable option. We can convert it to an Indiana. It's very hard to convert it to a neobladder because that urethra has been scarred down. I worry about the reliability of continence. So I don't usually convert it to a neobladder, but I can convert it to an Indiana pouch if somebody really doesn't want a bag.

Patricia Rios:

Thank you. Dr. Chan. Great question, Lisa. Kathy, this question is for you. Many of our support groups, or even speaking with patients, the topic of ostomy supply comes up often. As a matter of fact, I think from one of our participants, one of the questions that this person submitted in advance was the retirement homes and their ability to deal with ostomies. Any thoughts around that?

Kathleen Manuel, RN:

Yeah, that's a big issue. We also have that issue when our patients go to a skilled nursing facility or even home health. They often don't get supplies routinely. So we have to intervene. I would say when they leave the hospital, make sure that they have a one to two week of supplies with them that they can use. We see our patients fairly often, follow up clinic visits postoperatively, so we can give them some product when they come back to see us.

Ongoing, if they're in a skilled nursing and most home health's are mandated to supply those ostomy supplies or catheters, whatever they're using. So you just really have to get in touch with a case manager from the hospital and, or facility and really just be on them to get those supplies ordered and available for them. It's hard to get it done.

Patricia Rios:

Similar to that, I think a question that came up is can you pre-order supplies if you're going to travel for a while, or is that limited to a insurance company? Can you provide some insight around that?

Kathleen Manuel, RN:

Yeah, some of the insurance companies will allow you to order 90 day supply at a time, so that can help. I have had patients who have mentioned to their insurance company that they are traveling and have gotten away with getting more supplies.

Patricia Rios:

Good to know. So there's a question about the right bag supplies. How do you find the right bag supplies? What does that mean?

Kathleen Manuel, RN:

So when you're in the hospital having your diversion, and if you have an ileal conduit and, or any of the diversions, you may need supplies. If there's a wound ostomy nurse that works at the hospital, those nurses will help with your care, be assigned to your care and find the right product. Everybody's a little different and everybody needs different supplies. So it's helpful if there's a wound ostomy nurse at the facility or someone at least that knows the different product lines so that they can help the patients.

It may change over time. We may have to change it in a couple months. The stoma gets smaller over six weeks. So we're constantly measuring, looking, looking at body. If you gain weight, you may have to have changes. Lose weight, you might have to have changes. So just need somebody to constantly follow up with. It could be a wound ostomy nurse through a home health agency or out in the community or in a facility like ours.

Dr. Kevin Chan:

Yeah, I would add, Kathy, actually on every follow-up visit I see with my patients, Kathy, they almost are more excited to see Kathy than me. She'll come in, take a look

at their stoma and really problem solve if there's issues. Just think about it this way, if you have a problem, there's probably thousands of people that have had that same problem.

That's where people like Kathy can be so helpful at problem solving it. Never think that this is the first time this has happened. Any problem you're experiencing, there's probably a solution. That's where ourtherapists are so helpful and Kathy is so helpful.

Kathleen Manuel, RN:

The other resource too are the main ostomy pouch companies. Coloplast, for example, or Hollister, they have ostomy nurses on staff. You can call those companies directly and they will ask you a few questions and then they will suggest product and then they can send it to your home. So that's another resource too.

Patricia Rios:

Thanks for sharing that tip, because I think that often comes up. I think Dr. Chan is very fortunate to have you, Kathy. Some patients don't have a Kathy with easy access, so where can they turn? So the resources that you mentioned I think are excellent. Are there any others that we should be aware of?

Kathleen Manuel, RN:

United Ostomy Association of America has a list of all the wound ostomy nurses, I believe, or a number of them and the cities where they live, and some can be called to assist. I think that that would be the next place I would call, but I would first probably call straight to the company. They're Coloplast, Hollister, Convatec, whatever company they're using.

Patricia Rios:

Great, thank you. Last question related to that, is a patient able to switch suppliers for their ostomy bags?

Kathleen Manuel, RN:

Yes, they can. It is a little bit dependent on insurance companies and what insurance patients have, but for the most part, they do have options.

Patricia Rios:

Great. Thanks for answering that. Dr. Chan, so if you're using a section of intestine, does the patient have dietary restrictions or require specific nutrition monitoring because they have less of an intestine for absorption and the process of digestion?

Dr. Kevin Chan:

Yeah, that's a good question. So this is a pretty well-studied question in terms of metabolic changes. We use the distal ileum that seems to have the least amount of metabolic consequences. So it shouldn't change bowel habits. People may have heard of short-cut syndrome where people get diarrhea because they don't have enough time to reabsorb the water. We can safely use up to three feet of small intestine without having that problem.

So in general, there aren't significant bowel changes. Even when we use the ileocecal valve, which is that junction between the large and small intestine between liquid and formed stool that we use for the Indiana pouch, even they have pretty formed bowel movements. This segment of intestine historically is thought to be where B-12 is absorbed.

So some people can get this special kind of pernicious anemia from B-12, lack of B-12 absorption. So we will check B-12 levels periodically in their routine labs just to make sure they don't develop this. Honestly, I would say this is pretty rare. In general, there's no dietary restrictions. Honestly, I don't think really huge changes in their bowel habits. I think they'll typically get back to normal.

Patricia Rios:

Okay. Thanks for that. Now I want to switch gears a little bit to the concept of shared decision making. I think that was one of the themes of the presentation. Thank you for highlighting all the things that patients should consider and also highlighting what the ideal candidate would be for the different types of reconstructions.

So could we start with, and I would love to hear both of your thoughts on how do you define shared decision-making, particularly as it relates to bladder cancer treatment? What are those key components that make a true shared decision-making?

Dr. Kevin Chan:

Right. I always like to bring up this story. When I first started, I used to just present the three options, and a patient said to me, "If you're the doctor, shouldn't you be telling me what to do?" It's interesting, there definitely is an element where I think that's important and quote, unquote, that's not shared decision-making.

I think where the shared decision-making comes in is I always tell patients, "Listen, I'm here. I spend an hour with you because I want to know about you. I need to learn what makes you happy." That's really what needs to be shared is, "Hey, you have a role in this decision-making based on a lot of things."

Ultimately there is more than one right option for patients. So they are an incredibly important part of that decision making. It's not just me saying, "This is what you get." That's why I consider it shared decision-making is that they have a critical voice in things that we recommend, but also they get to make the final decision. I don't know. What do you think, Kathleen?

Kathleen Manuel, RN:

Yeah, I then meet with them for an hour, and I usually follow Dr. Chan. I start by just going over if they made a decision with Dr. Chan and do they understand that decision because it's a lot to take in. There's a lot of information given to them. It's very helpful to have a family member or friend or somebody with the patient so they can absorb some of this information. It can be very overwhelming.

Honestly, some of them aren't really clear on the three different diversions. They don't really understand them. It was just too much. So then I go over them again, show them pictures, show them pouches, show them catheters and just listen to what they're saying. Then again, like Dr. Chan said, just what does their day to day look like? Try to get to know them.

Do they just want to hang out with their grandkids? Do they want to play the pickleball? Whatever it is, I try to get to know them a little bit better. Then they always ask me, "What would you do?" I tell them, I am not going to tell you what I would do because you're the one going to be living with it. They want to know that, but I never share.

During that time, we try to come to a decision with what their needs and wants are, but sometimes they don't decide on that visit, and that's okay too. They can get in touch with us, Dr. Chan or myself, and let us know if they've changed their decision, if they went home and talked to other family members or other ostimates or peers that have diversions. Maybe their minds have changed, and that's fine too, but the decision is theirs ultimately.

Patricia Rios:

Thank you both for addressing that. You mentioned the caregiver or a loved one, so I was wondering what advice would you give the caregiver and loved one so that they could support their loved one through the decision-making process? Sometimes

perhaps the caregiver or loved one may have a different perspective. What advice have you given patients?

Dr. Kevin Chan:

I think this is an interesting question, and I don't know if I have the answer. I think you nailed it, which is, many times it's a child and the parent. The parent's the patient. Quite honestly, when they ask me, as they ask Kathy, they'll say, "If you were me, what would you do?" Which is a different question of, "If I were your dad, what would you do?"

Which it's a very different question, because me as a child, I don't care about my dad's quality of life. I just want to see him there every day. I want to have conversations with him. Honestly, I am not even thinking about him having a bag. As a child I'd say, "I just want the safest thing possible. You're going to get the bag."

If you are the patient, you may say, "You know what? I don't think I want the bag. I'd rather have this." So that's where I think there can be a discrepancy with that loved one and not... I think most family members, honestly, it's pretty intuitive to be pretty nurturing to their decision-making.

I think when the patient's pretty healthy and active, I think the kids really and the family members defer to the patient and let them make the decision. I think it's when they're more frail and have medical problems, they're like, "Hey, I know you're thinking about a neobladder, but maybe this isn't a good decision."

So I think in general, family members and friends are really honestly the patient's best advocate. They're almost the outside observer saying, "Hey, this is probably better." That's why it's so important to have them. Definitely we can sometimes get discrepancies with that group. Kathy?

Kathleen Manuel, RN:

Yeah, agree. I would say too, part of our, in the shared decision-making process is for us to evaluate their family support or their friend's support. I mean, that is critical in the recovery phase for really all these diversions, but maybe more so in long-term with the pouches, the Indiana pouch. So I think that's also an important key step. Really I feel like the patients support team is just really looking to do what they want to do, whatever makes them happy.

Patricia Rios:

Thank you for the thoughtful answers and really for spending this hour with us, Dr. Chan and Kathy. I want to make sure that I give enough time for each of you to share what would be your takeaway message from this conversation that you want our

listeners to remember as we conclude today's webinar. We'll start with, how about you, Kathy?

Kathleen Manuel, RN:

Okay. Well, I think it's important, again, to have support with you when you're going to these meetings with the doctors and get all the information. There's also written information that can be taken home. Really go over that, whether it be that day making a decision or go home and make a decision. Make sure you tell your story, the patient story, what you do during the day, what your goals are. If you play sports, let us know any hobbies you have so that we can help you with those decisions.

Honestly, I think with all these diversions, the life can go on as it did. Ileal conduit, Indiana, neobladder, all the things that you want to do, you can do with those. The big thing with the ileal conduit, everybody asks me, "Can I swim?" Yes, you can swim. You can swim with all these diversions. I really don't think there's any limitations on any of them, but it's important to advocate for yourself and make the decision for yourself. We can help you along the way if you need it.

Patricia Rios:

Dr. Chan?

Dr. Kevin Chan:

Yeah, that's perfect, Kathy. I would say my big thing is it really is my expectation that we're going to cure you of this disease. So I want you to put a lot of thought into this reconstruction option to make sure it's something that's going to allow you to do all the things you love after surgery. I want to tell patients that you literally will just be seeing me every six months and telling me what you did on vacation. That's really our expectation is that you're going to get back to life as you know it.

I know it's really hard to imagine that when you're getting all this information, but that's the message I want patients to know when we finish talking is, listen, you're going to get back. This is just a short chapter in your life that you're going to get through, and we're going to be sure you're happy with this.

Patricia Rios:

Thank you both for spending again this hour with us and for sharing vital information.

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