



Question and Answer

Stephanie Chisolm:

I deeply thank you so much. Dr. Kutikov, that was phenomenal and I think you really did such a great job of explaining all of those complications and everything else. I think the underlying message that I heard, and I hope that the participants here is kind of you wouldn't take your Jaguar to the mechanic on the corner. You go to somebody that does this on a regular basis. You really want to go to somebody who has that experience if you're going to have the surgery, because it is complicated. You don't want them to say, "I read about that in a journal once." Then, "Sure, I can do that. I'm a doctor." You want to go with somebody who has an awareness of what the problems are so you can circumvent them certainly. I think that that came through very closely and very clearly. Let's get to some of the questions. We have a kind of a unique question. There's a participant with only one kidney and their GFR is holding at 27. I guess they're indicating that they're going to have a cystectomy. If they choose to have the stoma and need dialysis, I think this is a good recommendation in terms of getting in the team approach. Because dialysis can be run by the nephrologist, correct? **Is it possible to do dialysis when you only have a stoma?**

Dr. Alexander Kutikov:

Yeah. Hemodialysis, the stoma won't affect your hemodialysis. I think the question is asking whether they can do peritoneal dialysis, which is basically putting dialysis fluid in the belly and having an exchange and do what a kidney does, but filter the toxins through the peritoneum. It's a great question. I think it's a real discussion with your nephrologist and your surgeon. It's a big risk that will not be possible because of adhesions. Regardless of what kind of surgery whether it's stoma or neobladder or an Indiana pouch, there can be adhesions that sort of prevent the peritoneal fluid from, lack of a better word, sloshing around the belly and exchanging. There will be pockets of scar where it will prevent one from getting peritoneal dialysis. It's a great question. There's a big wildcard there whether that's possible or not. A lot of people will do a little bit of hand waving to say, probably not, but something that can be tried. But generally, it's not a go-to. It's generally, once you have a lot of abdominal surgery, not a great candidate for peritoneal dialysis, but never say never. I mean, it's a discussion.

Stephanie Chisolm:

Okay. Good point. When you're doing a neobladder operation, what would cause the surgeon to not be able to spare the nerves. Everybody goes in with good intentions, but **what are some of the complications that come up that mean that you're not able to do that nerve sparing procedure?**

Dr. Alexander Kutikov:

Right. This gets to the question of, how good is nerve sparing during cystectomy and how effective it is in preserving erections. For instance, for prostatectomy, when we just take out the prostate, the nerves are very much localized right around the periphery of the prostate. That nerve sparing tends to work quite well. The problem with these nerves, is they sort of spread around the bladder and despite all efforts to spare the nerves, sometimes the erections just suffer greatly. Obviously there's scenarios where nerve sparing is abandoned, like there's disease that's sort of encasing the nerves, there's radiation scarring those kinds of things. But even if the nerves are spared, one needs to be counseled appropriately that it is no guarantee that one will have erection. Now, there are certainly patients after cystectomies who have a relatively good erections. But even in the best of hands, there's a big wild card of whether that nerve sparing will be effective. Now, again, as I mentioned in my talk, it doesn't have to be the end of personal life. Even without erections, one can be intimate. There's lots of ways to get erections back. But this is really some of the predictors of erectile function are really age, ability to nerve spare, function before surgery. Those kinds of things need to be integrated and really need to be discussed on an individual basis with a patient.

Stephanie Chisolm:

BCAN has done a couple of programs, specifically relating to sexuality for both men and women, and they're on our bcan.org website. That's a good point. Okay. I understand the repair of parastomal hernias is very involved with the potential for long-term post-op stay, nearly equivalent to the radical cystectomy itself. Please discuss what's involved in repairing these hernias especially if you don't use the mesh to begin with.

Dr. Alexander Kutikov:

Right. This is exactly why a lot of us have enthusiasm for doing the mesh upfront. It makes the surgery a bit longer, but it sort of prevents this issue down the road, that again, happens in 25% of folks. Yes, it's an involved operation and I'm very fortunate to have a general surgery colleague who's very adept at doing these at Fox Chase. But it takes an experienced surgeon who sort of understands the logistics. A lot of times it can be done laparoscopically and actually kind of get all the adhesions and get all the scarring off and get the bow out of the hernia and actually put a good mesh there. But yeah, this is a very nuanced operation that needs an experienced hernia surgeon to do, because it's easy to make it too tight and actually obstruct the ileal conduit, which can have a lot of problems. It's easy to damage the bowel and have these prolonged hospital stays and have a lot of problems. I would really, especially here seek a center that has a lot of experience in fixing these because they're operations that require quite a bit of expertise.

Stephanie Chisolm:

Do the inguinal hernias add to the rate of post radical cystectomy hernias or contribute to other complications in general?

Dr. Alexander Kutikov:

Yes. Once you remove the bladder, what we call occult hernia, sometimes folks have these hernias. They're really not clinically symptomatic, and it's very hard to even diagnose them, but once you move the bladder, where all of a sudden the bowel snakes into this hernia defect in the groin, and you can develop them after cystectomy. Now, we take them ... Usually those are relatively simple to fix and those are outpatient procedures. But a challenge comes up if somebody has a large hernia or symptomatic hernia before cystectomy. Again, this needs a multidisciplinary approach where it can be fixed. You sort of have choices. You can fix it before cystectomy. You can just fix it during cystectomy. You can fix it after cystectomy or forego fixing it altogether and just monitor it. Again, that really sort of needs an individualized approach. It depends on the size of hernia. It depends on how symptomatic it is. It's important. Usually, at least in my practice, I work with that hernia surgeon who helps me with the parastomal hernias, and we kind of figure out a plan for each patient. Sometimes the plan is different just depending on the circumstances.

Stephanie Chisolm:

Excellent. Great. Thank you. I think we have time for a couple more questions. **For people with a metastasis to a nearby lymph gland, is removal off the table since now we're already dealing with systemic cancer, or is that still an option down the road with other treatments?**

Dr. Alexander Kutikov:

Terrific question. When somebody has a lymph node positive disease, a cystectomy is still an option. Cystectomy shouldn't be done upfront. This is definitely something where a patient at most centers who'll receive chemotherapy first. I'll speak to our center. This is, approaches differ and there are sort of risks to each approach here. But at our center, we generally give chemotherapy and then we gauge the response. In the right patients, when the response is favorable, we actually offer surgery. Now, it's a discussion. It's a discussion whether the patient would want to go through surgery when the risks of kind of systemic progression are quite high. But again, a very sort of individualized decision. But especially the younger patients with great responses generally proceed with cystectomy.

Stephanie Chisolm:

One of the programs we do have on our website is a couple of things where some of our experts are also talking about prehabilitation and preparing for cystectomy. I'm going to kind of blend this question with something else. In terms of getting ready to go back to their normal activities, sometimes bladder cancer patients are a little bit older. They may have other comorbidity. **What's the typical time for getting back to their normal everyday activities. Is there something they should avoid doing when they've had a cystectomy?** Is there anything you recommend for getting yourself ready for anybody who's on this call who is awaiting a cystectomy in terms of making sure that you're going to have the best outcomes by preparing your body? What is there to do out there?

Dr. Alexander Kutikov:

Yeah. It's really important and terrific question that I probably won't do justice in just a few minutes, but I'll tell folks this. The one thing I do want to communicate is, this is an incredibly challenging period in people's lives. I mean, this is one of the hardest things that really humans go through. I mean, a cystectomy isn't just a giant operation, in the postoperative course, it's fraught with issues. Before one

gets wind back in their sails, it can be months. I mean, sometimes it's weeks, but you got to be prepared for months. I tell folks it's physical exhaustion, sort of dovetailed with an emotional exhaustion. There are people that have never been depressed in their life, and this is the first time that they really feel profoundly depressed. It's important to sort of make sure that you're self-aware and that you seek help. Most centers that do these surgeries have support and will get you through this very dark time. It really is. That what I really encourage folks to remember that no matter how sort of difficult the situation is, the clouds always lift. Sometimes it takes three or four months. What's challenging is that physically you can see the surgeons back and see the nurses back, and everybody says you look great.

You feel terrific. Then you go home and you just don't feel like your old self. You feel like you'll never get your energy back. You feel like you'll never have sort of the kind of the love for life that you had before surgery. You will, it just really takes a long time. Yes, the prehab and there's lots of efforts to try to kind of redirect the arc of this recovery and quicken it. But sometimes it's very difficult and the best thing is to really surround yourself with as good of a support group as you can have, and try to be as active as possible and just give it time and give yourself sort of time to recover from this just very large operation.

Stephanie Chisolm:

Great. Well, Dr. Kutikov, this has been phenomenal. We appreciate you sharing your experience with the entire bladder cancer community.

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