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### Stephanie Chisolm:

I have a quick question. You talked about the qualitative interviews and somebody is very excited about processing all of that data from those interviews. When do you think we might expect to see a publication on that? And should we start thinking about scheduling you for the fall to do a follow-up interview?

### Dr. Bochner:

Well, it's interesting. So we did take an early pass at some of that data and there's been some information published from that, but we're still working our way through a lot of that. And I'll tell you a little piece of that data which I thought was fascinating. And as a surgeon who's always interested in how my patients did, I, by no means would claim to be a quality of life expert. But fortunately, I surrounded myself from people who really understood this field. And one of the things that did come out is that people's frame of reference on how they should be doing significantly impacted how they sort of navigated this whole experience, okay? So for instance, if people come into surgery viewing themselves as, the people I need to compare myself to are the 60 year old guy, my workmates, right? Who are all healthy and they're working and running around, and that's what I need to be like, right?

That's kind of an unrealistic comparison for what they're about to run through, right? Whereas if people recognize, okay, I'm about to have major surgery and I'm going to need to cut myself some slack. And now my point of reference is a previously healthy person about to undergo some major treatment. And it's okay if I take a little break from being Superman or Superwoman for a while. As they begin to travel through that journey, they begin to accept things easier or becomes more difficult. So for instance, if they suffer a setback, they have an infection let's say, after surgery, the Superman frame of reference, that really challenges them to be able to absorb some of that recovery, whereas people who have voiced to us that they recognize that this is a big surgery, it's going to take some time to recover, but I'll eventually get there, they were able to navigate things better.

And what that told me was the importance of being able to give people a realistic view of what this surgery is going to put them through, right? To not tell them that, "Look, it's a six week recovery and you're going to be back at work and everything will be great." That's not the reality. That doesn't help folks, but to be able to say, "Look, here's a realistic view of what this recovery's going to be like, and you'll get back to be the mother or the grandmother or the daughter. And get back to work and enjoy

the things you want to do, but it's going to take some time, okay? And you have to expect that you're going to need a little bit of help maybe during this." So setting expectations was really important.

### **Dr. Bochner:**

And this was... Even though I kind of always sort of knew this as a physician, this was the first time to really show quantitative data on how setting those expectations realistically had impact on how people were reported their quality of life afterwards. So it's that kind of interaction that we get, which we would never get from these validated questionnaires, that we got from the idiographic data. And so we're working diligently through that. So hopefully by the summertime, we have some really nice papers that show them.

### **Stephanie Chisolm:**

So with that in mind, you're seeing these sort of level off lines here for these different characteristics that you looked at. Are there any plans to go at the 36 month mark or a five year mark back to those same people to see, are they really well adjusted five years afterwards?

### **Dr. Bochner:**

Yeah, it's a really great question. And this particular study sort of ended at the two year mark, but I do think that you're absolutely right, that even some of the longer term data would be very important to show. Again, Stephanie, this is such a broad group of people that get this disease. We kind of think of it as the older man who's been smoking for quite a while, but we see a lot of younger women who never smoked who like to run marathons who can get this disease as well. And what I feel is that they're on such different trajectories that we should not really be asking them the same questions. And so one of the ways that we're using this data, I don't envision having to give 14 standardized forms to everybody and a multiple hour interview.

What we're in the process of doing now is to take all this information and do what's called an item reduction evaluation, to be able to really find out what are the key questions that we need to ask. And I've challenged the statisticians that we're working with to try and personalize this, because I truly believe that that older widowed, maybe having some issues with his sexual function, retired male doesn't need the same set of questions as that younger mother working with a sexual partner does coming into this. And so what we're trying to design is what are the baseline questions that everybody would need to be asked? And then given their clinical characteristics, age, sex, partner status, sexual function status, things like that, that we can develop an algorithm that the next set of questions would differ.

One person would get this, because we know from this data that this is what's going to drive their quality of life. Maybe it's related to their sexual function. And in somebody else, maybe it's all about financial worries, right? That they need to get back to work so they can support their family. And that's what they're worried most about. Or maybe it's social functioning and being able to remain close to the people that are around them. I think knowing that and feeding that information back to the doctors, right? Hopefully we'll be able to then put the support, individualized support in place to be able to improve people's quality of lives in a more thoughtful way, at least that's my goal. So that's where we're hoping to go with this as time goes on.

### **Stephanie Chisolm:**

We're slowly starting to pick through some of the questions that are coming in. And there was one that came in really early. And I just wanted to see, you were doing this study at Memorial Sloan Kettering in

New York City. It is perhaps one of the most diverse locations in our country, because there are people from everywhere and of all races and ethnicities. Was there a good representation across race and ethnicity in this study that maybe you need to do a little dive into those aspects, see if there's any differences in there?

### **Dr. Bochner:**

So, a lot of referral centers, you'd be surprised that the group of people we end up seeing may not be as diverse as we would've hoped from a study standpoint, right? So a lot of minorities are underrepresented in this particular subset. A lot of these folks are Caucasians. We don't have nearly the same level of African-American, Asian or Hispanic groups that will make their way into Manhattan for care. And I think that that's probably not uncommon amongst a lot of the tertiary referral centers. And so we lack a lot of that. And so this brings up a really great point, Steph, which is that ultimately what we love to do is to develop this useful tool and then export it. And try and get that information at all different sites, right? At the referral center level, but also at the community care center level and the rural clinic settings, right?

Because, you're absolutely right. Just because this group of people is telling us this at our center, this may differ from group to group and from site to site. And we need to collect that information, because we realize that the vast majority of cancer care in the United States happens outside of the academic centers. It happens out in the community. And so it does raise an interesting question, are these outcomes transportable everywhere? And the answer is, I'm not sure that they are. With all major surgical procedures, whether it's Whipple for cancer surgery or the pancreas, or removal and replacement of the esophagus, any kind of major surgery, surgical volume at the center, surgeon's volume can affect outcome, right? Experience of the surgeon, experience of the team can affect outcome.

What I would like to believe is that this is not specific to Memorial, that there are lots of very dedicated surgeons that we have in the United States and throughout the world who are focused on this type of surgery, on developing a team that supports people throughout the hospital care, throughout their postoperative care is a really big team that's required to provide this long-term support. And it's out there, it's at different centers throughout. But I also hope that patients can see this and people recognize this. These should be your expectations, right? And I think that as you begin to look around where you're going to get your care, it's important to have this data, right? Not just to know that, I'm going to be okay, but you want to go to a place where you can feel reasonably comfortable that these can be achieved as well.

### **Stephanie Chisolm:**

This is awesome. Rick, do you have any questions coming up? Because I've got a few more coming in.

### **Rick Bangs:**

No, this has just been fantastic. And I love the opportunity for patients to kind ask questions and the doctors to kind of explore around these individual areas, because it kind of puts some context around what is quality of life, so. But no questions.

### **Stephanie Chisolm:**

Right. And you did factor in people's overall experience like, if they have a partner and some of those other things. And so I think that those are addressing some of the questions that are coming in. So that was sort of considered when you were looking at again, sexual functioning or even just quality of life

when you've got somebody living with you. And so that was part of that initial... You had a diagram, a little chart that showed all the different characteristics at the beginning of your slides, I think. If I'm recalling correctly.

**Stephanie Chisolm:**

Yeah. So married and partnered. So it was a deeper dive. So there is that ability to look in there to see, do you have a partner who can help you out? And as you were mentioning, sometimes over time partners don't have to do as much for the patient who might have an ileal conduit because they get more confident in changing their appliance and managing that. Obviously with a neo-bladder or an Indiana Pouch, these are some things that the patient needs to learn how to take care of for themselves. And so looking at it from that perspective, do you have a sense overall about how many women that are able to have a neo-bladder that come out of your study?

**Dr. Bochner:**

Yeah. I mean, I think that what we have found is there's some very specific selection criteria that we use as for women who would be an appropriate candidate. And in large part, there are tumor factors that are associated with it. We have to make sure that the area where the bladder and the urethra comes together, that's the area we're going to divide at the time of surgery so we can remove the bladder. That area has to be free of disease. And so knowing that their cancer is away from that area is critical. That they have good urinary control before surgery, right? So their normal bladder and pelvic floor support is in place. And that they potentially have the ability to perform catheterizations if they need to, okay? So they have to have some manual dexterity to be able to do that.

We do know that women still have a little bit higher risk of needing to catheterize compared to men. We're desperately working out the mechanics of why that occurs. But I think that if you meet those criteria, we tend to go ahead and offer the neo-bladders in women. And as we've reported and other series have reported that women do quite well, other than the increased for catheterizations. But I have found that in the women who have the manual dexterity to be able to do that, it's an adaptation that they make. And again, as we saw in this data, the body image issues, which sometimes is quite important for many folks, not just women, but for men as well.

**Stephanie Chisolm:**

And women. Right.

**Dr. Bochner:**

Absolutely. That the trade-off of eliminating the external appliance to learn how to catheterize a neo-bladder, for many women, they're okay with that. Drives me nuts because I'd love to see them all perfect and emptying on their own, but there is a subset that may need to cath, so. Yeah.

**Stephanie Chisolm:**

So I think it's really clear that it does take time to get used to what we at BCAN often refer to as the new normal. When cystectomy is in order, when it's the best type of treatment to have, it does take time to adjust to life without a bladder. I think what's really important in your study is that there is quality of life even without a bladder. And so many people who are faced with that decision, that treatment decision don't think, how am I going to survive without my bladder? And I think it's really significant that you've done this study. We look forward to hearing more about some of these really qualitative aspects. And

maybe again, we'll schedule something for the fall. That'll give you time to get some publications out that you'd be able to share with us. And I definitely will keep all of our participants aware of that.

**Stephanie Chisolm:**

So this is wonderful. I see that we are at time. Dr. Bochner, this has been fabulous. I really, really think this was a great presentation. And Rick, thank you so much for joining us as our voice of Bladder Cancer Matters. We know that bladder cancer does matter and we will be hosting a podcast with Dr. Bochner over the next couple of months. So, keep an eye out for that. And we're going to develop a patient sheet that kind of does a summary, that's really a lay language sheet of what the study was all about. I'm working with some of Dr Bochner's fellows right now on helping to make that more a plain language for everybody.

